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## **DOCTORAL THESIS**

### **Employment Barriers and Support Needs of People Living with Psychosis**

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Employment Barriers and Support Needs of People Living With Psychosis

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This thesis is submitted to Bond University in fulfilment of the requirements of the degree of Doctor of Philosophy. This thesis represents my own original work towards this research degree and contains no material which has been previously submitted for a degree or diploma at this University or any other institution.

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The design and methods used in this research were approved by the Bond University Human Research Ethics Committee. APA 6 style has been used throughout except where organisational regulations stipulate otherwise.

### **Abstract**

Despite the de-institutionalisation movement which commenced in the latter half of the last century, people living with a psychotic condition remain one of the most marginalised groups in society. A major barrier to their social inclusion is a low rate of competitive employment. Surveys have found that most people living with psychosis desire to work, and there is increasing awareness that participation in meaningful employment may indeed constitute an integral part of their recovery. Although enhanced models of employment service provision have demonstrated improved ability to gain employment, rates of competitive employment for this group remain very low. This Australian study aimed to extend knowledge concerning employment barriers and support needs of people living with psychosis by investigating the subjective experiences of multiple key stakeholder groups. This included clients diagnosed with schizophrenia or bipolar disorder, carers of people living with these disorders, employment service providers, employers, health professionals and community members. A purposive sample of 137 participants representing these 6 stakeholder groups participated in 14 focus groups and 31 semi-structured interviews to explore their views on the perceived employment barriers and support needs. Focus groups consisted of four to ten participants drawn from the same stakeholder group. Qualitative data obtained from focus groups and interviews were analysed and interpreted using a social constructionist approach and assisted by the use of NVivo 10 software. Visualisations of the data in the form of tree maps, charts and models were generated to demonstrate salient findings. Three broad categories of barriers were identified: individual factors, interpersonal factors and systemic barriers. The most frequently referenced barriers to employment

were interpersonal in nature, notably stigma, followed by individual factors and systemic barriers. Among individual factors, personal attributes such as motivation and self-management skills were more commonly referenced than impacts of the condition itself. The most frequently referenced systemic barriers related to aspects of government policy. Support needs identified by participants were broadly conceptualised in terms of the need for culture change, employment support and systemic changes. The most commonly referenced support needs were for improved employment support, culture change to improve societal awareness and attitudes, and systemic changes, particularly in government policy. The results of this study were used to develop a broad theoretical understanding of the relationships between factors maintaining the status quo and to identify some possible directions for future developments to improve employment outcomes. The findings of this study indicate that broad-ranging changes would be needed to improve the employment rate of people living with psychosis.

Keywords:

Psychosis, Schizophrenia, Bipolar Disorder, Employment, Barriers, Support

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## **Part A**

### **Context and Methodology for the Study**

## **Chapter 1: Introduction**

The world-wide movement to close mental asylums, which commenced in the latter half of the last century, marked the end of an era of custodial treatment of those living with serious mental health conditions. The impetus for de-institutionalisation came from a number of influences including recognition of the deleterious effects of institutionalisation on patients, the economic burden of accommodating increasingly large numbers of patients, and the discovery of new drugs that made less restrictive treatment options possible (Goffman, 1961; Talbott, 2004; Tandon, Nasrallah, & Keshavan, 2010).

The emptying of mental asylums ushered in a new era of so-called “community care”. However, the objectives of the proposed community psychiatric services were general, with little articulation of specific goals (MacKinnon & Coleborne, 2003). In addition, historical records indicate that the decision to close mental asylums and return their patients to the community was not consensual, and that the community was neither consulted nor prepared for the move, either in terms of resources or education. Newspaper accounts at the time reveal community concerns, many of which remain today (Bowdidge, 1993; Hocking, 1993). The perception of community residents at the time of de-institutionalisation was that former patients were “dumped” in the community and that there was a lack of funding and support to assist them to assimilate into the life of the community. Through a process of trans-institutionalization, many found themselves in nursing homes or prisons while others became homeless.

Some thirty years later, in 2013, in spite of their physical re-location into the community, the social inclusion of this group remains far from complete. People living

with serious mental health conditions remain one of the most marginalised groups in modern society. Those who were once institutionalised are now over-represented in prison populations (Brinded, Simpson, Laidlaw, Fairley, & Malcolm, 2001; Heffernan, Anderson, Dev, & Kinner, 2012), amongst the homeless (Folsom & Jeste, 2002) and the unemployed (Morgan et al., 2011).

While some attempts have been made in recent years to improve the provision of housing and care for people living with a serious mental health condition, a major barrier to social inclusion has been, and remains, the low rate of competitive employment among people affected by a serious mental health condition (Morgan et al., 2011). Where once these citizens were physically excluded from mainstream society, they are now living in the community but still for the most part excluded from participation in the economic life and prosperity of society; arguably a more painful state than total separation. In contemporary society, many people living with psychosis lead socially isolated lives and lack meaningful employment of their time. Many are living on the fringes of society where a lack of social support places them at risk of non-compliance with treatment and renders them vulnerable to exploitation and victimisation (Morgan et al, 2010). Keynes (2002) observed that most people living with a serious mental health condition are reliant on social security payments and their existence has been described as languishing rather than flourishing. This situation, where people are placed on a disability pension and limited attempts are made to promote their social and economic participation, has been described as a form of benign neglect (Cook & Razzano, 2000). The large-scale unemployment characteristic of this sector has important social, economic and health impacts on individuals, families and society.

Decisions are often made regarding people living with psychosis on the basis of limited knowledge of their desires, attitudes and opinions. This research examines the views of people living with psychosis and of the many people associated with them in relation to obtaining employment, the barriers that restrict them, and their perceived support needs. The associated people studied include the carers, health practitioners, employers and employment placement personnel. This is an area that has received limited research attention despite the prevalence and expenditure associated with these disorders. An Australian survey of psychotic disorders, for example, found that an estimated 63,533 people with psychotic disorders received services from public specialised mental health services in a 12-month period, which represents an estimated overall prevalence of 4.5 cases per 1,000 population (Morgan et al, 2010). The total expenditure on supporting people with a mental illness in Australia, excluding indirect expenditure such as lost productivity, is estimated to be at least \$28.6 billion per year, which is equivalent to 2.2% of Australia's GDP (Medibank Nous Group, 2012).

The purpose of this study is to improve understanding of the current barriers to employment and employment support needs of Australians living with a serious mental health condition. The goal is to elicit and explore the job-seeking and employment experiences of Australians living with psychosis, with a view to identifying perceived barriers to employment and employment support needs. By consulting multiple stakeholder groups, this study aims to obtain a more comprehensive and in-depth understanding of the current barriers to employment and employment support needs. An overview follows of the key areas impacting on this current research.



## **Chapter 2: Literature Review**

Several key theoretical areas of relevance to this research were identified including research relating to the socio-historical context; epidemiological research; individual factors as predictors of employment; social-contextual factors; treatment models and approaches; desire to work and impacts of work; and psychosocial interventions.

### **The Socio-Historical Context**

Any attempt to understand the current employment situation of people living with psychosis would be inadequate without a critical analysis of the historical context in which it is situated. The interpretation, social function and sanctions applied to hearing voices have changed through the ages. According to Hage (1993), around 1300BC the hearing of voices was commonplace. The interpretation of voices at that time was that people were communicating the will of the gods and the phenomenon appeared to serve a useful collective function in promoting social cohesion. In biblical times, people heard voices calling them to serve God or to communicate the will of God to others. In the medieval era Joan of Arc claimed she heard the voice of God telling her to save France, with historical records providing no indication of mental ill health.

In non-Western societies, occupational roles exist where people who hear voices are remunerated for using this ability for the benefit of the community and are valued and respected for doing so (Jonker, 2006). Modern Western society is more secular and individualistic and there is less tolerance for these phenomena. Voices are interpreted as having no collective meaning, as being idiosyncratic to the individual, and for the most

part a sign of mental illness. Few are interested in the content of these voices and the preference is to eradicate them through medication.

The preoccupation of contemporary psychology with individuality has resulted in a tendency to forget the central role of social factors in shaping subjective experiences and behaviour (Jacoby, 1975). The construct of mental illness itself, although firmly entrenched in the consciousness of modern society is, historically speaking, a relatively recent development in the evolution of knowledge (Foucault, 2009). Likewise, the concepts of employment and unemployment are relatively recent social constructs (Szasz, personal communication, January 3, 2011). This social amnesia is evident in our modern education system. The study of mental aberration is confined to experts, which ensures that the significant history of social exclusion and inhumane treatment of the so-called insane goes unnoticed by the next generation. Coleborne and MacKinnon (2003) have observed how the carefully collected artefacts of the asylum era in Australia are now, for the most part, stowed away out of sight and out of mind, beyond public scrutiny and social consciousness.

Few would deny that the history of societal treatment of the mentally ill is a shameful one (Mental Health Council of Australia, 2005). It dates back hundreds of years to when the mentally ill were removed from society and placed first in work houses, and then later in mental asylums, where they were separated from mainstream society along with individuals with mental retardation, epilepsy and various forms of dementia (Lewis, 1988). There are many historical accounts of the filthy and overcrowded conditions of many of these institutions as well as the ridicule and bizarre treatments to which many unfortunate inpatients were subjected (Moran, 2001).

Talbott (2004) attributes the decline in psychiatric hospital populations in the United States to the impact of the community mental health philosophy, more effective psychopharmacological agents, legal reforms and, most importantly, economic factors including changes to funding arrangements. Moving patients out of state facilities and into the community enabled states to shift financial responsibility for the care of psychiatric patients to the federal authority. Talbott (2004) maintains however, that at the time of de-institutionalisation, there was inadequate planning for the provision of services in the community that were previously available in the state hospital including medical and psychiatric care, accommodation, employment, vocational and social rehabilitation. In reality, many of the former patients were subsequently trans-institutionalised rather than de-institutionalised, finding themselves in prisons or nursing homes. Others were relocated to boarding houses or became homeless. In Australia, it is clear from archival records that the community did not welcome this move (Bowdidge, 1993).

The situation has not changed much today as many people living with psychosis are still living on the fringes of society, significantly excluded from mainstream employment and over-represented in prison and homeless populations. Many are now residing in boarding houses and supported accommodation. A recent Danish study, which refers to psychiatric supported housing facilities as “the new asylums in the community”, found that mortality rates in supported psychiatric housing were ten times higher than the general population (Nordentoft, Pedersen, Pederson, Blinkenberg, & Mortensen, 2012, p.1).

During the era of the mental asylum, work constituted an integral part of the daily routine. Patients were used in various forms of unpaid labour such as building

maintenance, gardening, farming, laundry and workshop labour (Lewis, 1988). During the asylum era, work was generally recognised by medical personnel as having therapeutic value, which provided the justification for the unpaid labour of patients (Moran, 2001). Historical records indicate that in many of these underfunded institutions the authorities in fact relied on patients to perform certain maintenance functions. Indeed, there are even records of family members alleging exploitation of their relatives' labour while institutionalised (Moran, 2001), suggesting that patients were indeed capable of productive employment and played an important role in the maintenance of some of these institutions. In later years, various forms of occupational and industrial therapy were regarded as an integral aspect of the therapeutic environment in asylums (Gittins, 1988).

Moran (2001), in recording the history of nineteenth century asylums in Canada, states that the value of work was recognised in asylums and that superintendents encouraged their patients to engage in a variety of work-related tasks. Asylum design incorporated large farms, workshops and knitting and sewing rooms to facilitate work therapy. In these institutions, work was considered an important diversion from the "morbid associations of the diseased brain" (Moran, 2001 p. 83).

The role and importance of work in the lives of people living with psychotic conditions has changed since de-institutionalisation. The Burdekin inquiry (1993) found that people with psychiatric disabilities had not received the same level of funding and access to vocational rehabilitation services as other disability groups and that people with psychiatric disabilities were often denied access to vocational services since they did not meet eligibility criteria or because of lack of resources including suitably skilled staff. The inquiry reported inter alia: a lack of success of rehabilitation programs; vocational

rehabilitation services for people with disabilities focussed almost exclusively on meeting the needs of people with physical and intellectual disabilities; and agencies that did cater for people with psychiatric disabilities were overloaded and only assisted the least disabled. Other impediments identified were education, training and accommodation problems. Rose, Burdekin, Jenkin, New South Wales Parliamentary Library and National Inquiry Concerning the Human Rights of People with Mental Illness (Australia) (1993) identified the need for vocational rehabilitation programs to be structured to address the needs of people with mental illness, for greater access to employment opportunities and to acknowledge individual goals and preferences. The inquiry concluded, “The development of effective vocational rehabilitation programs will not only substantially assist the recovery of people with mental illness, it will go a long way to ensuring their equal participation in the community” (Rose et al., 1993, p. 413). Since the release of the Burdekin report, limited progress has been made towards the re-integration of people recovering from psychotic conditions into vocational roles and the economic life of the community (Morgan et al., 2011).

An exception to this was the experience in Trieste, Italy where, following de-institutionalisation, 50% of people with a severe psychiatric condition were employed in an array of social firms or affirmative businesses. Warner and Mandiberg (2006), in reviewing the growth of the social firm movement, record how social firms were first developed in Northern Italy during the 1970s for the dual purpose of employing people with a disability and performing a necessary social service or producing a useful product. Social firms are based on the principle that over one third of the employees are people with a disability or labour market disadvantage. Employees earn a fair market wage

regardless of their productive capacity. Trieste cooperatives initially received a substantial public subsidy; however, by 1994 they were generating \$5 million in annual revenue, and by 2004 the subsidy had decreased to zero. Some emerging social firms may receive training subsidies. In this model, workers are provided with needed accommodations in a supportive atmosphere and a sense of community is fostered in the workplace. This model has since gained prominence in Europe and by 2005 there were approximately 8,000 social enterprises employing about 30,000 people with psychiatric or other disabilities. (Warner & Mandiberg, 2006)

### **Epidemiological Research**

Epidemiological studies in developed countries consistently report employment rates of less than 20% among people living with a serious mental health condition (Marwaha & Johnson, 2004). Although concerted efforts have been made in recent years to improve models of employment support for this group, rates of competitive employment in developed countries remain very low. A 2007 report by the Australian Bureau of Statistics revealed that only 15.9% of people diagnosed with schizophrenia were in part-time or full-time employment compared with 53.3% for all disability types and 95 % for all Australians of working age (Australian Bureau of Statistics, 2007). Waghorn, Chant and Jaeger (2007), using data extracted from three large scale Australian national surveys, found that people with a diagnosis of schizophrenia or bipolar disorder were at extensive labour force disadvantage. They found an unemployment rate of 84.5% among people with a diagnosis of schizophrenia and 74.6% among people diagnosed with bipolar disorder. They concluded that the employment rate of Australians without long term health conditions and disabilities is 2.7 times greater than among people with

bipolar disorder and 4.7 times greater than among people diagnosed with schizophrenia. Lloyd and Waghorn (2007) found that young people with psychiatric disabilities are at particular disadvantage in terms of rates of participation in vocational training, higher education and seeking or maintaining employment.

A 2010 Australian national survey of psychotic disorders based on a sample of 1,825 people receiving treatment for a psychotic disorder at seven catchment sites during the period March to December 2010 revealed that 32.7% had been in paid employment during the preceding year and that 21.5% of respondents were employed at the time of the interview (Morgan et al., 2011). In this study the unemployment rate was estimated to be five times that of the general population and a government payment was the main source of income for 85% of the sample. Waghorn et al. (2012), using data extracted from the above study, report that 21.24% of people with a diagnosis of schizophrenia and 26.33% of respondents with bipolar (mania) had engaged in labour force activity in the four weeks prior to the survey.

The adverse impacts of unemployment on mental health generally were highlighted in a 2007 National Survey of Mental Health and Wellbeing conducted by the Australian Bureau of Statistics. The survey, which gathered information from approximately 8,800 Australians in the general population aged 16-85 years, revealed significantly higher rates of anxiety and depression among unemployed than among employed respondents (Australian Bureau of Statistics, 2007).

Surveys reveal that people with psychosis are at higher risk of poor physical health (Morgan et al., 2011). It has been suggested that poor general health may be due to inactivity, substance misuse or iatrogenic effects of anti-psychotic medication (Morgan et

al., 2011). Poor general health in turn has been found to hinder employment (Waghorn, Lloyd, Abraham, Silvester, & Chant, 2008 ).

Substance abuse constitutes a significant barrier to employment, even among individuals unaffected by psychotic experiences (Henkel, 2011). Morgan et al. (2011), in an Australian national survey of psychotic orders, found that over half the participants (50.2%) reported a lifetime history of alcohol abuse or dependence while 56.4% reported a lifetime history of drug abuse or dependence.

Research indicates that having a criminal history (Solomon, 2012) and being homeless (Glomm & John, 2002) constitute barriers to employment in the general population. Individuals with psychosis are over-represented in prison populations (Brinded, Simpson, Laidlaw, Fairley, & Malcolm, 2001; Forsythe & Gaffney, 2012; Heffernan, 2012) and among the homeless (Folsom & Jeste, 2002), thus compounding their employment disadvantage. It remains unclear to what extent these co-occurring conditions, rather than the mental health condition itself, account for the low employment rate among people living with psychosis.

### **The Importance and Value of Work**

Research consistently indicates that most people living with a serious and persisting mental health condition such as bipolar disorder or schizophrenia would like to work in regular paid employment. A recent study found that 43.4% of a sample of 80 respondents with long-term psychiatric conditions living in supported housing stated they would like paid employment as their main activity in the future (Meehan, Madison, Shepherd, & Siskind, 2010). The 2010 Australian national survey of psychotic disorders revealed that the top three challenges reported by participants for the ensuing twelve



months were financial matters (42.7%), loneliness/social isolation (37.2%) and employment (35.1%) (Morgan et al, 2011). Results of the 2010 Survey of High Impact Psychosis (SHIP) study revealed that 68.1% of respondents wanted to work (Waghorn et al., 2012).

The association between economic disadvantage, unemployment and poor mental health has been demonstrated in numerous studies (Australian Bureau of Statistics, 2007; Platt & Hawton, 2000). The causal direction of these relationships however remains less clear. There is some empirical support for the “drift hypothesis” in terms of which people who are vulnerable to mental disorders are considered more likely to have difficulty maintaining employment and therefore tend to drift into unemployment and low socio-economic status (Aro, Aro, & Keskim, 1995). On the other hand proponents of the social causation hypothesis maintain that factors associated with unemployment and low social status generate psychological distress which in turn predisposes them to mental disorder (Fryers, 2005; Wadsworth & Acghenbach, 2005; Jenkins et al, 2008).

Two theoretical perspectives have dominated research into the effects of unemployment on psychological well-being namely the latent deprivation model proposed by Jahoda (1982) and the Fryer’s agency restriction model (Fryer, 1986). Jahoda (1981), building on the work of Robert Merton (1957), proposed that in addition to the manifest benefits of employment in the form of financial rewards, employment provides a number of beneficial latent functions, which she identified as time structure, social contact, collective purpose, identity/status, and activity. Jahoda (1982) considered that deprivation of the latent functions of work during unemployment causes psychological distress. Several researchers have investigated the relative importance of

deprivation of the latent versus manifest functions of work in predicting psychological distress associated with unemployment (Creed & MacIntyre, 2001; Creed & Klisch, 2005; Hassall, Muller & Hassall, 2004; Paul & Batinic, 2010). Fryer (1986) on the other hand proposes an agency restriction model which posits that psychological distress among the unemployed is better accounted for by the negative effects of poverty on personal agency and inability to project a future. Creed & Macintyre (2001) suggested an integrated theory may be useful in understanding psychological distress associated with unemployment.

Leading theorists in the field of psychiatry have endorsed the importance of work in promoting mental health. In his writings, Freud recognised the value of work:

Laying stress upon importance of work has a greater effect than any other technique of living in the direction of binding the individual more closely to reality; in his work he is at least securely attached to a part of reality, the human community (Freud, 1930/1957 p. 34).

Szasz (1973) wrote, “The greatest analgesic, soporific, stimulant, tranquilizer, narcotic, and to some extent even antibiotic-in short, the closest thing to a genuine panacea known to medical science is work” (p. 60). Kennedy-Jones, Cooper, & Fossey (2005), in a qualitative study of the worker role among people diagnosed with schizophrenia or a severe mood disorder, identified that work provides personal meaning: a sense of purpose and achievement, regular activity and structure to the day, a strengthening of the sense of self, an opportunity for social interaction and a sense of belonging.

A 2010 position statement from the Royal Australasian College of Physicians, based on a review of the research evidence investigating the relationship between health

and employment, states that “the evidence is compelling: for most individuals, working improves general health and wellbeing and reduces psychological distress” (Royal Australian College of Physicians, 2010, p.7). The paper asserts that work, in general, is good for health and wellbeing and that long term work absence, work disability and unemployment, in general, have negative impacts on physical and mental health. In relation to mental health conditions, the report states, “Overall, the message is that suitable work is good for the health and wellbeing of those experiencing mental ill health.” The report cites research indicating that suicide in general is increased six times in longer term unemployment and that, among young men out of work for more than six months, the risk is increased forty times. The report suggests that on the balance of evidence “unemployment causes, contributes to or accentuates these negative health impacts” (Royal Australian College of Physicians, 2010, p.12). Other benefits of work may include reduction of stigma among employed individuals. Perkins, Raines, Tschopp, and Warner (2009) pointed out that more research has focused on factors likely to increase social stigma towards people with psychiatric disabilities than on factors that destigmatise people living with these conditions. They administered a series of vignettes and a social distance rating scale to a sample of 404 adult interviewees and found that gainful employment reduces stigma towards people recovering from schizophrenia.

There is also increasing awareness that participation in meaningful employment may indeed constitute an integral part of recovery (Repper & Perkins, 2003). Research into outcomes of supported employment programs for people with serious mental health conditions has demonstrated improvements in non-vocational outcomes such as clinical symptoms, quality of life and self-esteem associated with competitive employment (Bond

et al., 2001). Brown, Monck, Carstairs, and Wing (1962) found that in homes characterised by high expressed emotion, having less than thirty five hours per week of face-to-face contact with a key relative was associated with lower hospital re-admission rates. Montero, Gómez-Beneyto, Ruiz, Puche, and Adam (1992), in a two year follow up study of a Spanish sample of people with schizophrenia, found that those who did not work tended to relapse more frequently than those who worked, particularly if there was high expressed emotion in the family. In an Australian study, Shankar (2005) conducted semi-structured interviews with 25 employees with psychiatric disabilities who were successfully sustaining open employment six months after completing a community based vocational rehabilitation program. All participants in this study reported improved relationships with family members as well as improved social status, skills and abilities.

Employment placement and support has also been demonstrated to have economic advantages in terms of reduction in the use and costs of mental health services (Bush, Drake, Xie, McHugo, & Haslett, 2009). A matched-control study of 150 hospitalised adults, which controlled for the number of previous psychiatric admissions, found that early psychiatric readmission rates were more influenced by residential and employment status than by the severity of the psychiatric disorder as measured by presence of psychosis and Global Assessment of Functioning (GAF) score (Schmutte, Dunn, & Sledge, 2010). The study found that unemployed participants were more than nine times more likely to be readmitted to hospital during the first year than employed participants.

The impact of macro economic factors on workplace wellbeing has also been a focus of study, and has highlighted the deleterious effects of work that is alienating, meaningless or aversive (Marx & Engels, 2012). Cotton (2012) maintains that while

work of high psychosocial quality is associated with increased employee resilience and improved mental health and wellbeing, “bad” work or work of poor psychosocial quality can be detrimental to psychological wellbeing. Honey (2004) pointed out that in the absence of a supportive work environment outcomes for employees with schizophrenia may not always be positive. There is also research which indicates that not *all* people who are unemployed experience heightened psychological distress, and that this relationship may be mediated by factors such as the quality of their previous employment experiences (Butterworth, 2011) and financial resources (Thomas, Benzeval & Stansfield, 2007). Butterworth et al. (2011), based on an Australian longitudinal national household survey of working age respondents, found that, overall, employed respondents enjoyed better mental health than unemployed respondents. The study also revealed, however, that people employed in jobs measuring lowest on a scale of psychosocial quality experienced poorer mental health than unemployed respondents, as measured on the Mental Health Inventory. This highlights the need for attention to workplace factors and, in particular, what makes for a healthy workplace if the mental health benefits of work are to be realised.

### **Treatment Models and Approaches**

**Medical model.** The medical model has been defined as a process whereby doctors, informed by the best available evidence, advise on, coordinate or deliver interventions for health improvement (Shah & Mountain, 2007). The history of psychiatry is replete with bizarre treatments such as purging, insulin coma therapy and lobotomy, all of which were implemented with the intention of health improvement. Tandon, Nasrallah, and Keshavan (2010) acknowledge that, even the evolution of modern

pharmacological treatments, has been based primarily on serendipity and intuition. Antipsychotic medication has proven relatively effective in treating the positive symptoms of psychosis (Tandon et al., 2010). It has also proven effective in decreasing violent behaviour (Torrey, 2011). However, the effectiveness of antipsychotic medication remains limited. Chaudhury (2010) reports that 25 to 30% of auditory hallucinations in schizophrenia do not respond to traditional antipsychotic drugs and that, even with the newer antipsychotics, a significant minority of patients continue to hallucinate. According to the Schizophrenia Research Institute (2010), “Up to 30 % of people with schizophrenia still experience hallucinations and delusions despite taking antipsychotic drugs”. Hearing Voices Network Australia (2009) report that, even when optimally treated with antipsychotic drugs, approximately 50% of people diagnosed with schizophrenia still hear voices. Lieberman et al. (2005) investigated the effectiveness of first-generation and newer antipsychotic drugs in the treatment of 1,493 patients with chronic schizophrenia. The researchers found that the majority of patients in both groups (74% overall) discontinued their assigned treatment within the eighteen month trial period owing to inefficacy, intolerable side-effects or other reasons, and that there was no significant difference between groups in terms of time until discontinuation of the treatment due to intolerable side effects. Given the current status of available medical treatments for schizophrenia, which often provide incomplete relief of symptoms, the current focus on treating symptoms with psychotropic medication tends to underestimate the importance of active acceptance of symptoms and living a meaningful life *in spite of* ongoing symptoms (Veiga-Martinez, Pérez-Alvarez & Garcia-Montes, 2008).

In terms of the medical model, treatment efforts usually focus on the elimination of clinical symptoms and the possibility of functional recovery in psychosis is often seriously questioned. The negative prognostications of traditional psychiatry are best exemplified by the views of Emil Kraepelin, who described schizophrenia as a progressively deteriorating illness culminating in various types of dementia (Kraepelin, 1919/1971). Cohen and Cohen (1984) attribute the reluctance of mental health professionals to challenge this negative prognostic view to the “clinician’s illusion.” This arises from selective exposure of clinicians to patients with the most severe presentations during times of crisis, such as hospitalisation for an acute psychotic episode, and less exposure to people who have recovered and are functioning well in the community (Cohen & Cohen, 1984 p. 1178). This may account for the pessimistic attitude and low expectations of employment amongst health professionals reported in several studies (Marwaha, Balachandra, & Johnson, 2009). Several researchers have found that mental health professionals often report people with psychiatric disabilities having unrealistic work expectations and goals, whereas surveys have revealed job preferences are mostly realistic and consistent with their skills and educational level (Lloyd & Waghorn, 2007; Mueser, Becker & Wolfe, 2001). Australian population surveys show that at any one time approximately 16-19% of people with schizophrenia and other severe mental health conditions secure employment and work in competitive employment, without having sought or accessed any form of employment assistance (Waghorn, 2011).

Existing literature suggests that health professionals, in their interventions with clients, tend to focus on alleviating clinical symptoms rather than encouraging social and economic participation. Health professionals may fail to protect their patients from long

term unemployment and may, inadvertently, actually push them into unemployment (Royal Australian College of Physicians, 2010).

Health professionals may not regard referral to employment services as part of their primary role, and attitudes of clinicians may not always be conducive to achieving employment outcomes (Marwaha, Balachandra & Johnson, 2009). General practitioners may also lack knowledge of local employment support services (Crawley, Fitzgerald, & Graham, 2007). King, Cleary, Harris, Lloyd, and Waghorn (2011) found that clients as well as clinicians lack information on employment-related issues and identified a need for pertinent information to be provided to clinicians and clients to facilitate access to appropriate employment services. Recent work evaluating an enhanced approach to the provision of individual placement and support for young people experiencing a first episode of psychosis has highlighted the need to respect client preferences. This can be done by offering the options of supported study, supported employment or a combination of both (Neuchterlein et al., 2008).

**Recovery model.** In contrast to the traditional medical model, there is new thinking about mental health and employment that has been called the recovery model. In terms of this model, individuals living with psychosis should be supported to recover a meaningful life *in spite of ongoing symptoms*. The emphasis in the recovery approach is on unlocking and maximising potential to live a contributing life. Proponents of this approach suggest that work may in fact be an integral part of the recovery process in these conditions (Repper & Perkins, 2003).

During the past decade, there has been growing interest in the concept of recovery as a process in which individuals, regardless of the severity of their condition or the



existence of ongoing residual symptoms or deficits, are supported to return to valued roles and independent living as soon as possible (Repper & Perkins, 2003). This approach provides more options for intervention and challenges the pessimistic prognostications, low expectations, passivity and disinterest in employment shown by many helping professionals.

The recovery model considers outcomes such as reintegration of the person into the community and quality of life as important measures of recovery (Repper & Perkins, 2003). Indeed, in this model, independent work or study may be considered an outcome measure of effective treatment. This approach increases the imperative on individuals to learn new skills and share responsibility for successful outcomes with other role players in the community such as employers, who are perceived as readily able to effect necessary adjustments. While employment is often considered by clinicians to be potentially stressful and likely to precipitate relapse, Slade (2012) argues that a recovery orientation requires health services to acknowledge the dignity of risk and to strike a balance between duty of care and positive risk-taking. Slade maintains that the goal of reducing all harmful risks involving people experiencing mental health issues is damaging and discriminatory. In the recovery model, setbacks are viewed as an inevitable part of the recovery process, and individuals are supported to return to work following absences due to episodic relapses of the condition. The focus in this model is less on symptom status than on measures such as of quality of life.

Leamy, Bird, Le Boutillier, Williams, and Slade (2011), on the basis of a review of the recovery literature, have formulated an emergent conceptual framework which they consider incorporates the key characteristics, processes and stages of the recovery

experience. The authors maintain that this model is theoretically defensible and provides a basis for future recovery-orientated research and practice. Some essential differences between the traditional medical model and a recovery model, including impacts on employment, are shown in Appendix A.

### **Role of Individual Factors**

Empirical research has focused on identifying individual variables as predictors of employment outcomes among people living with psychotic disorders. Christenson (2007), based on a systematic review of the literature, found that attention and negative psychotic symptoms were strongly associated with the capacity to maintain competitive employment. Based on this review, he concluded that there is strong evidence to argue that a neurocognitive profile should be obtained before planning work rehabilitation programs. The importance of cognitive factors as predictors of employment and the ability to generalise the effects of cognitive training to the workplace has, however, been contested by other researchers (Dickenson et al., 2010). Further research is necessary to clarify the contribution of cognitive training to employment outcomes. Research evidence on symptom severity, including neurocognitive factors, as predictors of employment outcomes is equivocal. Most of these studies have used a cross-sectional correlational design which restricts the ability to impute causal relationships. One could argue, for example, that less severe symptoms could be the outcome rather than the cause of a positive employment outcome.

Bio and Gattaz (2011), using a neurocognitive test battery to measure cognitive functioning of a sample of volunteers with clinically stable schizophrenia, found that participants who took part in a six month work internship showed greater improvement

after six months on measures of executive functioning, negative symptoms and quality of life, when compared with a wait-listed control group.

A number of studies indicate that employment rate is not directly related to symptom severity. For example, a study in urban India found no correlation between positive symptoms of schizophrenia, severity of neurocognitive factors and employment rates. The researchers tentatively suggest that the higher employment rates observed in their study compared to western societies may be due to social and economic factors, including the compelling need to work due to lack of disability benefits, and a supportive work environment (Srinivasan & Tirupati, 2005).

The Clinical Antipsychotic Trials of Intervention Effectiveness (CATIE) study found that participation in either competitive or non-competitive employment was associated with having less severe clinical symptoms, better scores on a composite measure of neurocognitive functioning and higher scores on a measure of intrapsychic functioning (Rosenheck et al., 2006). It was also found that a higher level of education was positively associated with competitive employment status. Other significant findings of this study were a negative association between receipt of disability payments and both participation in competitive employment and earnings among those who were employed.

Rutman (1994) identified the following barriers inherent in the condition of schizophrenia: cognitive, affective and interpersonal deficits; episodic and unpredictable nature of illness; iatrogenic effects of treatment; and inappropriate client values, attitudes and aspirations toward work. These findings were endorsed in a qualitative study conducted by Peckham & Muller (2000). In a survey of job coaches, Blitz & Mechanic (2006) found the following individual factors of relevance: client motivation,

expectations of work; self-efficacy; physical, cognitive and social skills; level of education; concerns about loss of entitlement to social security benefits. Henry & Lucca (2004) in a qualitative study of people with psychiatric disabilities and employment service providers identified inter alia the impact of symptoms, work skills, attitudes and experiences.

On the basis of a review of relevant research, Grove, Secker, & Seebohm (2005) suggest that psychological variables such as self-efficacy and goal orientation may be more important than previous work experience or clinical status in determining employability. These authors also identified other psychological factors such as work attitudes, expectations and motivation as influencing employability, although pointed out that these factors, rather than being used to exclude people, can be fostered through engagement with appropriate vocational services. Whilst self-belief may be influenced by the attitudes and perceptions of others, it is not determined by these views. Existential theory affirms that the will to meaning is stronger than the most adverse circumstances in human experience (Frankl, 1982).

Waghorn (2002), using survey data obtained from a sample of 782 Australians with psychotic disorders, found that the most useful clinical predictor of vocational recovery was self-reported course of the condition, with those reporting a chronic deteriorating course being 4.9 times more likely to be unemployed than those reporting a single episode with good or unknown recovery. Non-clinical variables which contributed to prediction of employment outcome included age, education and skills, marital status, premorbid work adjustment and having had one's needs met by a vocational service in the preceding year. In a three year follow-up study conducted in Finland, it was found

that the probability of competitive employment was higher for patients with a diagnosis of schizophrenia who at the time of discharge were not on a disability pension (Honkonen, Stengard, Virtanen, & Salokangas, 2007). Marwaha and Johnson (2004), in a review of the literature, found that premorbid social functioning and work history were the most consistent predictors of employment among people with schizophrenia. Studies have also shown a positive association between level of education and employment status in serious mental illness (Rosenheck et al., 2006).

### **Role of Social Contextual Factors**

There is evidence that social contextual factors play an important role in influencing employment outcomes among people living with serious mental health conditions. The World Health Organisation International Classification of Functioning, Disability and Health (ICF) acknowledges the significance of social and environmental factors in influencing participation and activity (WHO, 2001) - see Appendix B.

The importance of psychosocial contextual factors in employment is borne out by evidence that employment rates for people living with psychosis in some underdeveloped countries are higher than in Australia. A study of 88 patients with chronic schizophrenia attending an outpatient and day care facility in India found that, in spite of demonstrable cognitive dysfunction, 67 % were employed, mostly in mainstream employment. This finding was tentatively attributed to social factors, including the compelling financial need to be employed and the presence of a supportive work environment (Srinivasan & Tirupati, 2005). Suresh et al. (2012) found that almost two-thirds of a sample of 201 patients with schizophrenia receiving community based treatment in rural south India had satisfactory work functioning at three year follow up. Tsang et al. (2007) identified cross-

cultural differences between US and Chinese employers in terms of their perceptions and willingness to employ a person with psychosis.

A longitudinal study of employment outcomes among a large sample of discharged schizophrenia patients in Finland pointed to changed work conditions in recent years as a possible explanation of the low and declining rates of competitive employment observed in this study (Honkonen et al., 2007). These authors consider that characteristics of the modern work environment such as decrease in suitable manual jobs, high demands for cognitive competence and interpersonal skills may have decreased work opportunities for those suffering from severe mental health conditions. A similar trend has also been reported in the United Kingdom (Marwaha & Johnson, 2004). Waghorn (2009), using data files provided by the Australian Bureau of Statistics, found that improved labour market conditions in Australia between 1998 and 2003 was associated with increased labour force participation rates among healthy individuals and those with anxiety and affective disorders, but did not substantially increase employment among people living with schizophrenia.

Henry and Lucca (2004), using 6 focus groups of consumers and 6 focus groups of employment service providers, found a range of environmental barriers to employment related to the service system, entitlement programs, non-human resources and social stigma. These include factors such as relevance of inpatient work-related interventions, quality of relationships with service providers and programs, lack of communication and co-ordination across services, lack of community services such as adequate public transportation, financial disincentives imposed by the US federal entitlement system and lack of family support. On the basis of interviews and a mail-out survey of 28 job

coaches employed by supported employment providers, Blitz and Mechanic (2006) identified the following structural barriers to employment for individuals with psychiatric disabilities: access to reliable transport, availability of continued treatment and access to child care, affordable housing and health services. Employer flexibility was believed to be associated with better prospects of obtaining and retaining employment.

Research has also investigated the impact of the family and other social contextual variables on employment of people living with psychosis. Shankar (2005), in a study of employees with psychiatric disabilities, found that family concerns following a relapse situation may reinforce reluctance to return to work. Rutman (1994) articulated several difficulties posed by: conceptual and operational differences between disciplines; tensions and discontinuities between major service systems working with people with psychiatric disabilities; work disincentives created by social security; difficulties assessing work readiness; and impact of stigma on work opportunities. Kennedy-Jones, Cooper, and Fossey (2005), using case studies of people living with psychiatric disabilities, identified the importance of support from significant others.

An extensive body of research exists on the negative impacts of social stigma on people diagnosed with mental health conditions. Peckham and Muller (2000) identified employer concerns and stigma toward the mentally ill as significant barriers. The classic work of Goffman on the management of what he terms the “spoiled identity” of mental patients is no less relevant today than it was fifty years ago (Goffman, 1962/1986). More recent qualitative studies overseas confirm the disempowering effects of social stigma and discrimination including its diverse impacts on employment of people living with a severe mental health condition (Schulz & Angermeyer, 2003; Seeman, 2009). Research

into public attitudes indicates strong negative stereotypes including perceptions that people with a mental illness are unpredictable, aggressive, violent, dangerous, unreasonable, less intelligent, lacking in self-control and frightening. Studies of social distance indicate that few people would recommend someone with schizophrenia for a job (Schulz & Angermeyer, 2003). Mental health professionals have also been found to be guilty of stigmatising attitudes towards their patients (Lauber, Braunschweig & Rossler, 2006).

On the other hand, it has been suggested that integration of people with mental health conditions into gainful employment could play an important role in changing social attitudes and reducing the stigma associated with these conditions (Corrigan & Penn, 1999; Perkins et al., 2009). Schulz and Angermeyer (2003) have suggested that in order to challenge the exclusion of people with schizophrenia from important life opportunities, it is particularly important to support them in the field of employment.

### **Psychosocial Interventions for People Diagnosed With Psychotic Conditions**

Most treatment approaches for psychotic conditions have focused on case management and the use of medication, and there has been a lack of psychological applications generally, including in the area of provision of employment support.

**Psychological interventions.** Clinical psychology has tended to follow the lead of the medical model in its focus on the identification, classification and treatment of negative emotional states, with the goal of intervention generally being the eradication of symptoms. The provision of psychological interventions for psychotic conditions was not seriously considered until fairly recent efforts to examine the efficacy of cognitive behavioural therapy (CBT) for psychosis (Haddock & Slade, 1996). Recent research has



demonstrated the efficacy of work-focussed CBT in facilitating return to work in non-psychotic populations (Lagerveld, Blonk, Brenninkmeijer, Wijngaards-de Meij, & Schaufeli, 2012). Despite much lower employment and employment retention rates among people with psychotic conditions than among the general population, there is a paucity of research investigating the effectiveness of psychological interventions in improving employment outcomes in this group.

Psychotherapeutic approaches such as Acceptance and Commitment Therapy (ACT) consider behavioural activation in the pursuit of valued goals as being the key to attaining a vital and meaningful life. In the ACT approach mindfulness techniques, values clarification and behavioural activation are used with a view to improving psychological flexibility rather than necessarily achieving symptom reduction (Hayes, Strosahl, Bunting, Twohig & Wilson, 2004). This approach provides more options for intervention, as behavioural activation in the service of valued goals is an available option regardless of the severity of symptoms, efficacy of medical treatment and prognosis for the condition. This is particularly important in chronic mental health conditions where remission of symptoms through medication is often only partial (Bach & Moran, 2008). Previous approaches assumed that patients need to be symptom-free before they are able to engage in goal-directed behaviour such as employment. The ACT approach suggests that helping professionals should support individuals to develop a more comfortable relationship with their condition, identify valued goals and initiate behaviours consistent with these goals in spite of ongoing symptoms.

Motivational deficits have long been known to constitute a major functional impairment in schizophrenia (Lysaker & Bell, 1995). Motivational interviewing has been

found to be a highly effective approach to behavioural change in a range of settings including substance dependency and health behaviour change (Miller & Rollnick, 2002). More recently, motivational interviewing has been proposed as an appropriate therapeutic approach to engaging clients with schizophrenia in vocational rehabilitation services (Corrigan, 2005; Lloyd, Tse, Waghorn, & Hennessy, 2008).

**Vocational interventions.** During the past decade there has been a change of focus from investigating individual factors as determinants of employment outcome to investigation of the employment support needs of people living with psychosis. Qualitative studies have provided insights into some key support needs of vocational programs for people living with psychosis. Peckham and Muller (2000) identified possible four categories of coping strategies: educating employers, anxiety management, social support and stress management. Respondents reportedly also identified four categories of solutions: support in the form of a hot line, education of employers and community, personal training and environmental stability. The previously mentioned qualitative study by Henry and Lucca (2004) identified quality consumer-provider relationships and individualised employment services as being the most important facilitators of achievement of employment goals. Their findings highlighted inter alia: the importance of a good job match; employer willingness to make accommodations; improved communication and co-ordination of service programs; training and education opportunities; improved access to information about human service and entitlement systems; addressing issues within the entitlement system; and reduction of stigma and consumer empowerment.

Research indicates that the type of employment support provided is a stronger predictor of employment outcomes than any individual factors (Grove et al., 2005; Waghorn, 2011). There is an extensive body of research that evaluates the efficacy of approaches to the provision of employment support for people diagnosed with serious mental health conditions. Vocational interventions have typically followed the prevailing medical conceptualisation of serious mental illness. Aligned with the medical model is the traditional approach to vocational rehabilitation for people with psychiatric disabilities, which has also been described as the train-place model (Corrigan & McCracken, 2005). In this approach, symptoms must be adequately controlled and pre-vocational skills training provided prior to any attempt to place an individual in employment. This usually includes pharmacological treatment and interventions to address specific cognitive and social skills deficits associated with the condition. In the traditional model, a prolonged period of prevocational support and training may be required before the individual is deemed work-ready. In this model, the health professional is the gatekeeper who defines a person's competence to work. As symptom control in psychotic disorders may at best be partial, even with optimal treatment, this creates the dilemma of how to determine when a person can be considered work-ready. This model allows for client referrals to employment services to be rejected on the basis of criteria of unknown validity. It also may require the person to move through a series of work environments with graduated levels of stress prior to entering open employment. This process itself requires perseverance and adaptability on the part of the individual to adjust to different work settings and colleagues. The rehabilitation process may be lengthy and result in prolonged periods of unemployment. Unemployment in turn may

result in de-skilling, decreased self-confidence, secondary depression and reinforcement of the avoidance behaviour that is characteristic of many psychiatric disorders. In this model, failure is usually attributed to client characteristics. Tensions can readily occur when referrers adopt an inclusive citizenship perspective and providers adopt a competency perspective, or when referrers fail to refer due to a competency perspective based on diagnosis, with resulting waste of human potential (Kirsch, Krupa, Cockburn, & Gewurtz, 2010). Bond (2004) points out a lack of research evidence to support the generalisability of skills learned in vocational rehabilitation to the work setting. There is also some evidence that lengthy prevocational programs that forestall work lead to consumer dissatisfaction (Corrigan & McCracken, 2005). Due to the primacy of symptom control in this model, there is also concern about the impact of work-related stress and its possible role in relapse and re-hospitalisation.

An alternative approach is the Individual Placement and Support (IPS) model, which has also been called the place-train model, in which individuals with psychotic conditions who wish to work are rapidly placed in suitable jobs and provided with ongoing support to sustain work (Corrigan & McCracken, 2005). This model which was developed and first implemented in the United States by Bond (1998) is characterised by the following eight key principles (Bond, Drake, & Becker, 2012):

- The focus is on competitive employment.
- Eligibility is based on consumer choice. A zero exclusion policy applies, in which any client who expresses a desire to work is regarded as eligible for supported employment and should not be excluded on the basis of severity of illness, residual symptoms or other measure of work readiness.

- The goal is rapid job placement.
- Supported employment is integrated with clinical treatment and there is close co-operation between the mental health and employment sector.
- Job finding and all assistance is individualised with attention paid to consumer preferences.
- Clients receive individualised job support.
- Assistance is provided with work incentive planning.
- Employment specialists contact employers for purposes of systematic job development.

The IPS model is the most extensively researched service model for the provision of employment support for people with serious mental health conditions. Randomised controlled studies have consistently revealed that supported employment is more effective than traditional vocational rehabilitation approaches in assisting people with serious mental illness with the transition into employment. Indeed, the evidence for the efficacy of supported employment is such that it is now recommended in the clinical practice guidelines of the American Psychiatric Association as an evidence-based treatment for schizophrenia (Lehman et al., 2010).

Bond et al. (2001) reported that previous studies evaluating the conversion of day treatment programs to supported employment found no increase in rates of adverse clinical outcomes, while other studies have found that participation in employment programs does not increase rates of hospitalisation. The relative effectiveness of IPS compared with other forms of vocational rehabilitation has increased since the program was first developed (Bond, 2004; Bond, Drake, & Becker, 2008; Bond et al., 2001).

Bond et al. (2008), reviewing the results of 11 randomised controlled studies involving high fidelity IPS services, found that 61% of clients achieved competitive employment compared to 23% of a control group receiving other vocational rehabilitation services. Research into the effectiveness of IPS programs has demonstrated that high fidelity supported employment programs in which vocational and clinical services are highly integrated have achieved better employment outcomes (Cook et al., 2005).

A review of psychosocial treatments for schizophrenia conducted by the Schizophrenia Patient Outcomes Research Team (PORT) concluded that the IPS model is an evidence-based intervention and recommended that it should be offered to any person with schizophrenia who has the goal of employment. The study found that “there is no evidence that engagement in supported employment leads to increased stress, exacerbation of symptoms, or other negative clinical outcomes” (Dixon et al., 2010, p. 51). However, the review found that, whilst supported employment has achieved superior outcomes to other approaches, long-term job retention and economic independence have not been clearly demonstrated (Dixon et al., 2010).

The application of the IPS model has proved more effective in the US than in other countries, with outcomes of randomised trials demonstrating employment rates in the US of 62% compared to 47% in non-US studies (Bond et al., 2012). The diminished effectiveness of IPS model in non-US countries has been attributed by Bond et al to labour and disability policies that impede return to work and substandard implementation of IPS fidelity principles.

While much of this research has been conducted in the United States, there are studies that have investigated the implementation of the IPS model in Australia (King et

al., 2006). Some ongoing difficulties have been experienced with implementing this approach in Australia. Major challenges identified were a lack of integration between disability employment services and community mental health services and difficulty implementing the zero exclusion policy due to current employment assessment processes (Waghorn, Collister, Killackey, & Sherring, 2007). Waghorn et al. also found that no Australian site had developed a systematic approach to the provision of benefits counselling. Waghorn (2011) attributes a decline in performance statistics of disability employment providers in recent years to failure to implement high fidelity evidence-based practices as well as perverse incentives in the current government funding model, which rewards employment providers for inputs rather than outputs. A multi-site randomised controlled study in Queensland demonstrated that the mean competitive employment rate achieved by IPS services reaching minimum implementation standards was 54% compared with 30% for a control group receiving regular disability employment services (Waghorn, 2011). Furthermore, consistent with findings of international studies, most participants receiving IPS services worked 20 hours or more per week and most jobs lasted 20 weeks or more. The implications of this study are that employment rates can be improved and sustainable outcomes achieved when DES programs offer high fidelity IPS services.

Several researchers have demonstrated support for the use of the IPS model as a component of early intervention for young people with first episode psychosis (Browne & Waghorn, 2010; Killackey, 2010; Killackey, Jackson & McGorry, 2008; Rinaldi et al., 2010). The main recommended modification of the IPS model for young people is the

inclusion of individualised support for formal education and training (Neuchterlein et al., 2008).

Despite the relative success of the IPS model, research studies indicate that even in the most effective supported employment programs, between 40% and 60% of jobseekers who desire work do not find employment (Larson et al, 2007). This realisation has led to attempts to enhance existing individual placement and support (IPS) programs. Currently, research is in progress to determine whether motivational interviewing, when provided as an adjunct to the Individual Placement and Support (IPS) model of supported employment, enhances employment outcomes for jobseekers with a diagnosis of schizophrenia when compared to IPS plus psycho-education (Glynn, 2012). Another proposed enhancement is the incorporation of cognitive training. Research into the efficacy of cognitive remediation training has so far yielded mixed results. Some researchers have demonstrated sustained improvements in measures of cognitive functioning, symptoms and quality of life after completing a cognitive retraining program (McGurk, Twamley, Sitzler, McHugo, & Mueser, 2007; Poletti et al., 2010). Tan (2011) found that individuals with schizophrenia who received a cognitive retraining intervention showed improvement in cognitive functioning and functional outcomes but not quality of life, when compared with controls offered an exercise intervention. Others have found that improved performance on cognitive training tasks does not generalise to measurable neuropsychological or functional outcomes (Dickenson et al., 2010). Some other less researched approaches to the employment of people with serious mental health conditions include social firms, transitional employment programs, peer support worker roles, and sheltered workshops. Transitional employment programs, such as those



provided in the Clubhouse model, offer short-term employment opportunities.

Clubhouses are local community centers that provide members with opportunities to socialise and support them in obtaining employment, education and housing. In this model, the employer is guaranteed job attendance and performance, with a staff member of the Clubhouse undertaking to cover an employee in the event of absences (Killackey, Jackson, Gleeson, Hickie, & McGorry, 2006). During transitional employment, the employee is paid at or above award wages, and when the placement ends is provided support to obtain independent work. A concern with these approaches to employment has been the limited prospects for career progression that may be associated with these approaches (Waghorn, 2010).

While most interventions to enhance employment outcomes have focused on meeting the employment support needs of the individual jobseeker, there is literature calling for broader environmental interventions. Rose et al. (1993) stated that, in order to be effective, vocational programs must recognise the interdependence of vocational needs with other aspects of life and for support in matters such as interpersonal skills, housing and finance, and advocated for greater access to a range of employment opportunities.

Shankar (2005) suggested that the social network has a critical role in influencing employment outcomes. Shankar identified that job tenure can be improved through having a good job match, access to a professional during times of difficulty and involving and educating the social network, including family and treatment professionals.

Workplace support needs were also identified such as support with interpersonal relationships, asking for assistance, requesting feedback on performance and negotiating reasonable accommodations (Shankar, 2005).

In spite of efforts to improve vocational interventions for people living with psychosis, labour market statistics in the current economic climate reveal a significant discrepancy between the number of jobseekers and the number of jobs available. In Australia in February 2014 there were 733,700 unemployed people but only 140,800 job vacancies (Australian Bureau of Statistics, 2014). This means that improved vocational support may influence which unemployed people find work but cannot reduce or eliminate unemployment and the associated public mental health costs of unemployment. There is growing interest in Australia in defining, locating and counting social firms. One recent study suggests that there are an estimated 20,000 social firms in Australia and that it is a mature and sustainable sector (Barraket, 2010). Warner and Mandiberg (2006), in reviewing the development and growth of social firms internationally, state that Korean legislation requires businesses to employ people with disabilities or pay a dividend which goes towards rehabilitation services including social firms. They also report that in Germany the government provides wage supplements for employees with disabilities as well as providing equipment purchase grants for social firms. The emphasis in the United Kingdom is currently on retention of employment following relapse among people with a serious mental illness. This requires the provision of appropriate support to return to the workforce as soon as possible after relapse, as opposed to dropping out of the workforce and reinforcing a sense of failure and incompetence (Repper & Perkins, 2003).

The research evidence indicates that IPS is the most successful employment service model to date. However, variable adherence to fidelity standards in Australia appears to compromise cost-effectiveness and much remains unknown about the impacts

of broader contextual factors on outcomes of IPS-based employment services. The emergence of social firms in Australia offers new opportunity to diversify employment opportunities for people living with psychosis and to investigate the cost-effectiveness and sustainability of this model.

### **Gaps in Research on Employment Barriers and Support Needs in Psychosis**

Much Australian research in the area of mental health and employment has focused on epidemiological studies and empirical studies relating to the implementation and outcomes of the Individual Placement and Support model of employment support. However, there have been relatively few Australian qualitative studies that have examined in-depth the barriers to employment and employment support needs of clients diagnosed with serious mental health conditions from the perspective of the clients themselves (Bassett, Lloyd, & Bassett, 2001; Honey, 2004; Peckham & Muller, 2000). Those that do exist have usually involved case studies or relatively small sample sizes. One qualitative study which focused on job tenure for people with psychiatric disabilities pointed out that greater depth would have been added to the study by including the perspectives of employment providers (Shankar, 2005). This suggests the need to adopt a broader approach which encompasses not only the views of clients but also other important stakeholders. Various stakeholder groups have accumulated collective knowledge on this subject, however, this knowledge has not been consolidated due to the historical segregation of sectors and different ways of seeing. Some studies have incorporated the views of employment service providers on barriers and facilitators to employment (Blitz & Mechanic, 2006; Henry & Lucca, 2004). However, there are no studies that have sought the views of multiple stakeholder groups including clients,

family carers, health professionals, employers and members of the community.

Furthermore, while some studies have attempted to determine facilitators to employment there are none that have directly asked participants what they perceive to be the main employment support needs of people living with psychosis.

There is also insufficient research on the impact of workplace variables on employment outcomes among people living with psychosis. A study by Kaye, Jans, and Jones (2011) examined the attitudes of employers towards employment of people with disabilities, however, there is little literature on the subject of employer attitudes and perceptions in relation to employment of people suffering from psychotic disorders. There is also little focus in the literature on work accommodations for people with psychological disabilities (Australian Safety and Compensation Council, 2007). For example, there is a lack of study of the effect of psychological interventions to support people with more serious mental health conditions to maintain their employment and to return to work following periods of relapse. There is also a lack of research on the outcomes of social firms in Australia.

Family carers are key informants in this area and to date the perspective of carers of people living with psychosis has not received much attention in the literature. The attitudes of community members also do not seem to have been sought on this matter. It is proposed that consideration of the perspectives of multiple key stakeholders would provide a more comprehensive understanding of the barriers to employment and employment support needs of Australians living with a serious mental health condition.

### **Chapter 3: Methodological Considerations**

#### **Constructivist Paradigm**

Constructivism is the epistemological perspective that has guided this research into employment barriers and support needs in psychosis. The constructivist approach is based on the premise that reality is socially constructed and that there are historical and socio-political forces which perpetuate and sustain social reality (Berger & Luckmann, 1967). In terms of the constructivist paradigm, truth consists in the consensus of multiple perspectives. The researcher, rather than striving to be a detached observer, engages collaboratively with participants to generate data that, instead of constituting immutable and timeless laws, is acknowledged to be specific to a particular time and context (Maxwell, 2005). This approach has been widely used in feminist studies and other forms of action research such as the study of minority groups, as a means of raising awareness and challenging commonly held ideas, beliefs and conventions. The constructivist approach challenges institutionalised belief systems, and allows new perspectives and insights to emerge in areas that do not readily lend themselves to the positivist approach.

#### **Why Qualitative Research?**

The qualitative approach is guided by constructivist assumptions. Qualitative research methods provide the means to elicit and attend to the discourses and socially constructed realities of participants and distil a consensus from their experiences. Qualitative research provides opportunity to fill gaps in the existing predominantly quantitative research literature by creating a research setting in which participants themselves have more scope to identify the key issues, direct the discussion and freely voice their opinions relevant to the research topic. Qualitative methods maximise the

opportunity for participants to play an active role in the research process and are very respectful of the lived experience of participants. The qualitative approach is also consistent with the demands of mental health activists, who maintain that people with a lived experience should be active participants in the design and conduct of research into mental health. A commonly heard slogan among client and carer advocacy groups is 'Nothing about us, without us'. This includes involvement at every stage of the research process, from framing the research question to interpretation of results. Through its collaborative style, qualitative research enables the capture of rich data regarding the subjective world of the various stakeholders, using their own language and narratives. It is an appropriate methodology to use with vulnerable clients as there is flexibility to adapt the approach to individual needs and circumstances. Qualitative research is an appropriate methodology to use to explore little researched or taboo subjects. The focussed attention provided in individual interviews and small groups maximises engagement of participants and provides a naturalistic setting in which the dynamic interchanges between individuals facilitate disclosure of views and opinions as well as provide opportunity for synergistic solutions to emerge. These methods can open up new areas for investigation that may not have been considered important at the outset of the project. It also allows for the identification of unexpected variables and has the flexibility to integrate these variables into the enquiry process. Qualitative research respects the complexity of interacting variables, and insights gained can help elucidate the multiple and dynamic interactions between people and their environment, enabling theory to be generated in areas that are poorly understood. Qualitative research can also be used for

triangulation purposes to validate the findings of positivist research, as well as highlight potential new areas for research.

The main limitation of qualitative research tends to be the smaller sample sizes and resultant difficulty in generalising findings. Another potential limitation is the inherently subjective nature of coding and interpretation of results. However, measures can be taken to avoid systematic bias, such as carefully considering participants to be included in the sample: actively seeking out participants whose views may oppose those of others already recruited to the study: and working with participants, co-researchers and collateral sources to validate findings.

Qualitative research methods have been used to investigate issues such as stigma (Schulze & Angermeyer, 2003); perspectives of people with mental illness on the benefits and drawbacks of employment (Honey, 2007); views and experiences of employment among people with psychosis (Marwaha & Johnson, 2005; Nithsdale, Davies, & Croucher, 2008); and employer experiences of employing people with mental illness (Tse, 2004). Davidson, Sells, Songster, and O'Connell (2005) have highlighted the benefits of the constructionist vis-a-vis the positivist paradigm in investigating recovery issues in mental health.

### **Research Questions**

Most quantitative research is based on a deductive reasoning process in which the researcher formulates a hypothesis based on an existing theory and then tests the hypothesis against empirical data. Qualitative research on the other hand usually involves a process of inductive reasoning. The researcher selects a research topic and then proceeds with in-depth exploration and analysis of the data with a view to discovering

patterns, themes and relationships in the data. During this process, the research question/s may be modified and hypotheses emerge, which are then tested against the existing data or by gathering further data. The process moves from the specifics of the data to more general principles and theoretical formulations. In qualitative research studies, hypotheses are generated as the research progresses, in the form of propositions which are further tested during the data collection process (Maxwell, 2005). The research questions in this study were:

- 1) What are the barriers to employment for Australians living with psychosis?
- 2) What are the employment support needs of Australians living with psychosis?

### **Reflexive Methodology**

The methodology used in the analysis phase of this research is reflexive methodology (Alvesson & Skoldberg, 2010). Unlike other approaches in qualitative research, reflexive methodology does not assume that data speaks for itself, that themes will somehow emerge naturally, or that the observer is neutral or value-free in analysing or interpreting data. Instead, reflexive methodology acknowledges that there are different ways of seeing, which are inevitably influenced by the past experiences and theoretical bias of the researcher. In this approach, the researcher is transparent and articulates, in advance of analysis, the particular theoretical position from which the data will be viewed (Alvesson & Skoldberg, 2009).

Charmaz (2006) maintains that it is impossible for the researcher to approach qualitative analysis without being influenced by their own past exposure to theory and literature. She also cautions that in choosing to view the data from a pre-determined theoretical perspective from the outset, there is a risk that the researcher will be biased in



looking for and finding only data that supports a particular theoretical position. Instead she encourages the researcher to be “theoretically agnostic” and “theoretically playful” in approaching the data. This allows the researcher to develop categories which are informed by theory and then explore and check to see whether a particular category holds up against the data. As such one’s original epistemological position may change during the course of analysis depending on the best “fit” with the data.

Although consideration was given to a number of possible theoretical standpoints from which to view the data, the epistemological position which emerged as best fit with the data was consistent with the social constructionist approach described by Andrews (2012). The social constructionist approach is associated with the post-modern era in qualitative research and acknowledges the major influence of Berger and Luckman (1966). Social constructionism does not necessarily deny the existence of an objective reality or the impact of contextual influences but maintains that our experience of reality are socially constructed through the interactions of individuals and groups. It is less concerned with ontological questions and instead seeks to understand the world of lived experience from the perspective of those who live in it. In this approach importance is attached to everyday interactions and how language is used to construct social reality. This approach acknowledges that researchers are inevitably influenced by their own background and experiences and aims for their observations to be fair rather than objective. According to the constructionist view the researcher cannot pretend to be a blank slate, and should try to be aware of their own assumptions and perspectives from the outset (Charmaz, 2006). The social constructionist approach has evolved as a branch

of grounded theory, and is compatible with methods used in grounded theory which may be used to distil commonalities in the lived experience of participants.

Appreciative enquiry was used as a complementary approach to exploring the topic and answering the research questions. Van der Haar and Hosking (2004) describe appreciative enquiry as a variation of the social constructionist approach which adopts a more positive, collaborative and participative approach than conventional action research, and is regarded as more capable of generating innovative change. It typically frames questions that elicit positive narratives about past success experiences in order to identify key ingredients for positive change.

### **Focus of Study**

The term psychosis is used to describe a mental state which occurs in a number of different mental health conditions. Bipolar disorder and schizophrenia were selected as the focus for this study for the following reasons:

- Both are persisting conditions characterised by recurring psychotic episodes.
- These conditions are generally acknowledged by the medical and lay community as having severe functional impacts.
- Historical records indicate that people exhibiting psychotic symptoms accounted for a large proportion of patients in psychiatric hospitals (Hill & Laugharne, 2003).
- People who have been diagnosed with schizophrenia or bipolar disorder are at extreme labour force disadvantage, and greater occupational disadvantage than other psychiatric diagnostic categories (Waghorn et al., 2012; Waghorn, Chant, & Harris, 2009; Waghorn, Chant, & Jaeger, 2007).

- It was also thought that most study participants across all stakeholder groups would have some knowledge and/or exposure to either one of these conditions. This decision was vindicated by the responses of some community participants who acknowledged that they had knowledge of one but not both conditions.

The DSM-5 definitions of psychiatric terms such as schizophrenia, bipolar disorder, schizo-affective disorder and psychosis were used for purposes of this study (American Psychiatric Association, 2013). The distinction between these disorders is not considered to be of primary importance because the diagnostic entities themselves are subject to constant change, as evidenced by the current debate surrounding the American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders. An architect of DSM-IV and now leading critic of the newly released DSM-5, has stated “the way we label symptoms follows fickle fashions, changing quickly and arbitrarily.” (Frances 2013, para. 8). Several participants in this study observed that it is not uncommon for people to have different diagnoses assigned by the same or different clinicians over the course of time.

### **Linguistic Issues**

The language used in this thesis, while in a sense endorsing the health metaphor and the medicalisation of psychotic experiences, is used for pragmatic purposes as there is no other commonly shared and understood language in existence at this time. The term mental health condition as well as contemporary medical diagnostic terms such as schizophrenia and bipolar disorder, although themselves subject to ongoing controversy and debate, have been preserved for purposes of achieving a shared understanding of the

phenomena being studied. The concept of *serious* mental health condition raises further conceptual difficulties. Some common mental health conditions such as depression may be serious while other conditions commonly considered to be debilitating may be well-managed and have minimal functional impacts. Furthermore, seriousness, rather than being inherent in the nature of the clinical condition itself, may be a function of responsiveness of the condition to existing treatments, the perceptions or reactions of others or other broader social factors. For purposes of this study, the phrase *serious mental illness* will be used to refer to long term mental health conditions which tend to persist in spite of optimal treatment and are characterised by episodes of psychosis.

It is acknowledged the word *employment* can be interpreted as referring to a wide range of paid and unpaid work activities. However, in this study employment refers to any form of paid work.

## **Chapter 4: Design and Method of Study**

### **Design and Method**

Based on the literature review, key stakeholder groups were identified whose perceptions were deemed most relevant to the research topic. The following key stakeholder groups were identified: clients with lived experience of bipolar disorder or schizophrenia; family and carers of people with the aforementioned conditions; employers; employment service providers; health professionals; and community members.

Focus groups and in depth individual interviews were used to gather information on the perceived barriers to employment and employment support needs of people who have been diagnosed with a serious mental health condition. Focus groups were selected as a research method as they reduce the role of the researcher and may reduce the balance of power between the researcher and participants, allowing the voice of marginalised groups to be heard (Liamputtong, 2011). The purpose of conducting in-depth semi-structured individual interviews was:

- to capture any new ideas not already captured in the focus groups;
- to expand the range of people represented in the study;
- to include exceptional cases in the sample such as people living with a serious mental health condition who have fared well in employment;
- to involve employers who have provided exceptional support;
- to expand and corroborate ideas expressed in the focus groups; and
- to fill gaps in understanding and test emergent ideas and theory

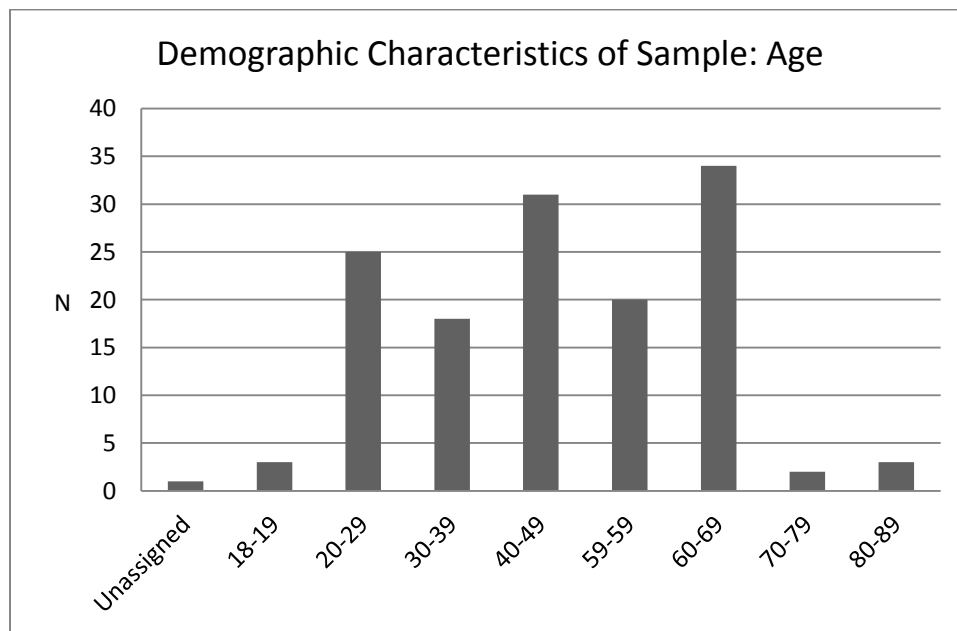
Kaye, Jans, and Jones (2011) suggest that employer attitudes may be influenced by social acceptability bias and therefore asked employers in their study about their perceptions of attitudes of *other* employers rather than about their own personal attitudes. Similarly, the questions posed in this study were of a general nature which removed any need for participants to respond in a defensive manner. It was clear from the frankness of many participants across all stakeholder groups that this goal was achieved. The synergy achieved in focus groups and flexibility of the interview approach generated rich data which might not have been possible had the researcher used a more structured approach.

For purposes of individual interviews, a semi-structured interview technique was used. Structured interview schedules were developed for each stakeholder group (see Appendices C-H). All interviewees were asked the same two main questions posed to the focus group participants as well as a selection of related open-ended questions drawn from an interview schedule designed for their specific stakeholder group. Approximately half the one hour interview was allocated to consideration of each of the main research questions. A responsive interviewing style was used, as described by Rubin and Rubin (2005). In this approach the interview is shaped by the concerns of the interviewee as well as the interviewer. The interview schedule was used to keep the discussion flowing and focused on the main research questions, and was flexibly applied to elicit information relevant to the participant's personal experience. A set of probe questions was developed to use if needed to explore new concepts and ideas. Spontaneous follow up questions were also posed to elicit in-depth information as required. Where appropriate, individual interviews also incorporated an appreciative enquiry component in the form of questions

designed to explore the key ingredients of successful work-related experiences (Reed, 2007).

### Data Collection

**The sample.** Participants were recruited by approaching individuals, community organisations and service providers in South East Queensland. To support the recruitment process, flyers advertising the research opportunity were developed and distributed by community organisations. An effort was made to include adult participants aged across the adult life-span range (18-84 years). The inclusion in the sample of a number of participants aged eighty years or over yielded useful historical information and insights relating to the topic. The demographic characteristics of the 137 participants are shown in Figures 1-4.



*Figure 1.* Demographic profile of sample: age group in years.

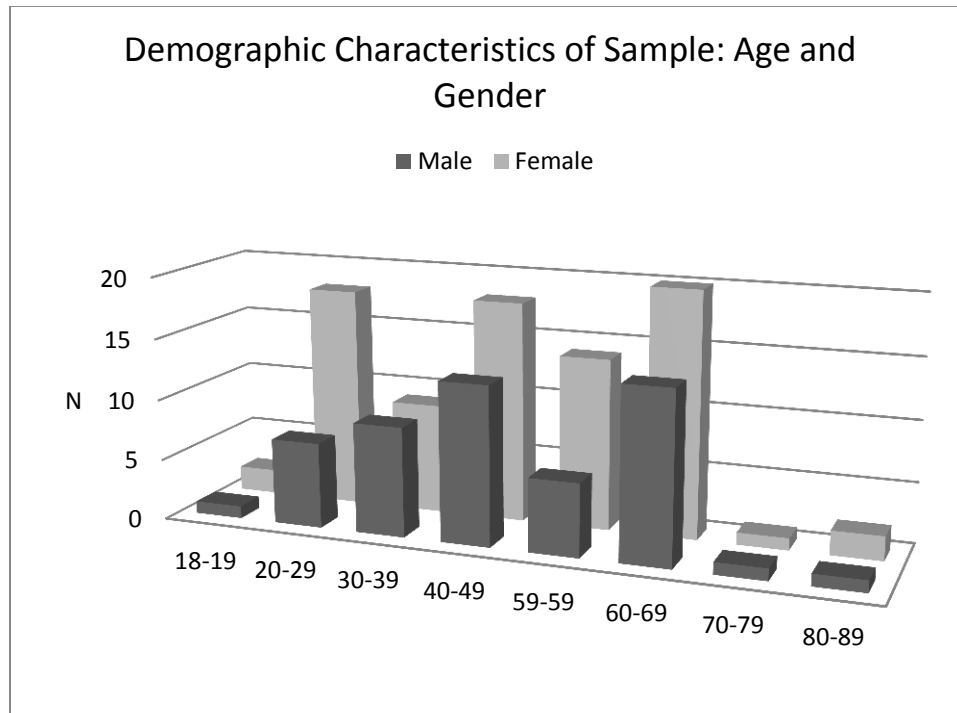


Figure 2. Demographic profile of sample: age group and gender.

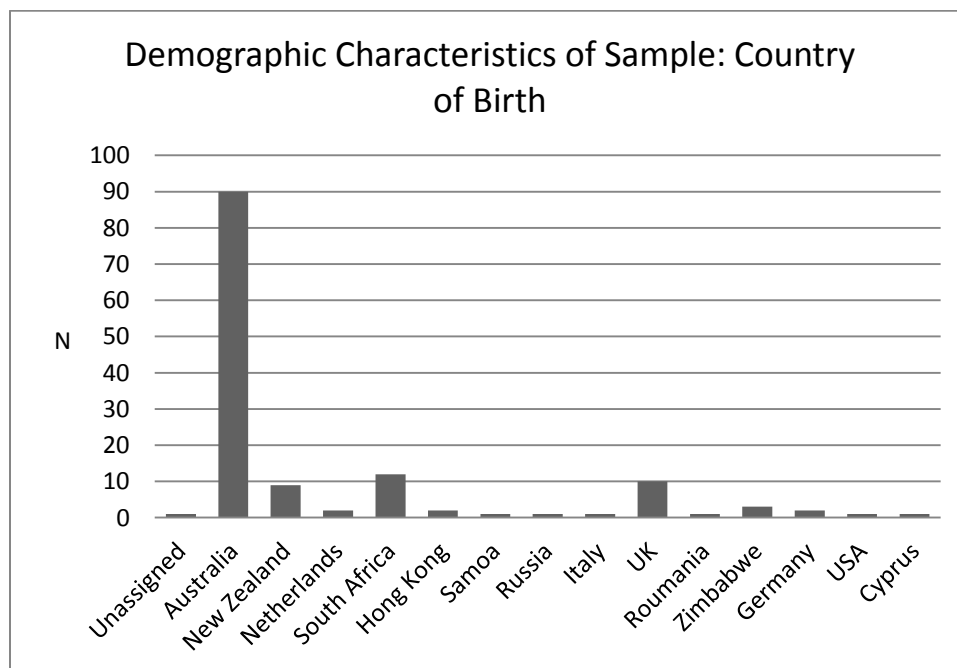


Figure 3. Demographic characteristics of sample: country of birth.



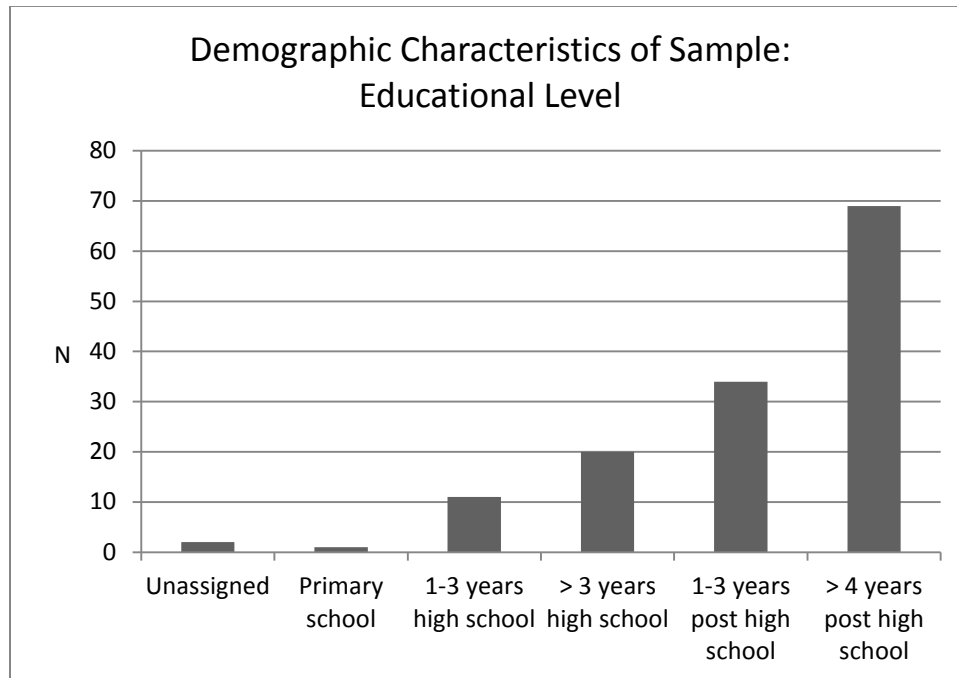


Figure 4. Demographic characteristics of sample: educational status.

All participants were provided with an explanatory statement outlining the nature and purpose of the study and were required to provide informed written consent prior to participation, including consent for the discussion to be audio-taped. In situations where a client had a nominee, consent of the nominee was required. Clients who were considered to be acutely unwell at the time of the study were excluded. Participants were also required to complete a biographical information sheet providing basic demographic information such as gender, age, and occupational status. The author, who is an endorsed clinical psychologist, was personally responsible for recruitment of participants, conducting the focus groups and individual interviews, and transcription and interpretation of the data.

Data collection proceeded in two stages:

- Stage 1- Focus groups.

- Stage 2- Individual interviews.

**Stage 1-focus groups.**

*Focus group sample.* A purposive sample of volunteers representing each of the following stakeholder group was invited to participate in focus groups:

- Clients who self-identified as having been diagnosed with schizophrenia or bipolar disorder. One client focus group consisted of out-patients of a community mental health service and a peer support worker; another client focus group consisted of members of a psychiatric advocacy group; while a third client focus group consisted of members of a non-government community support organisation (clubhouse). Participants included 10 people who disclosed a diagnosis of schizophrenia and 4 people who disclosed a diagnosis of bipolar disorder.
- Carers of people diagnosed with schizophrenia or bipolar disorder. Participants for the carer focus group were recruited through a carer support group.
- Employers. This focus group consisted of members of a business organisation.
- Employment service providers. Focus groups, comprising managers and employment consultants, were held at each of three disability employment service organisations.
- Health professionals. This focus group comprised staff employed in an in-patient psychiatric rehabilitation unit: occupational therapists (5), registered nurses (3) and an art therapist.

- Community members. Focus groups consisted of a neighbourhood group; a community service group; a group of university students; a church group; and a young adult group.

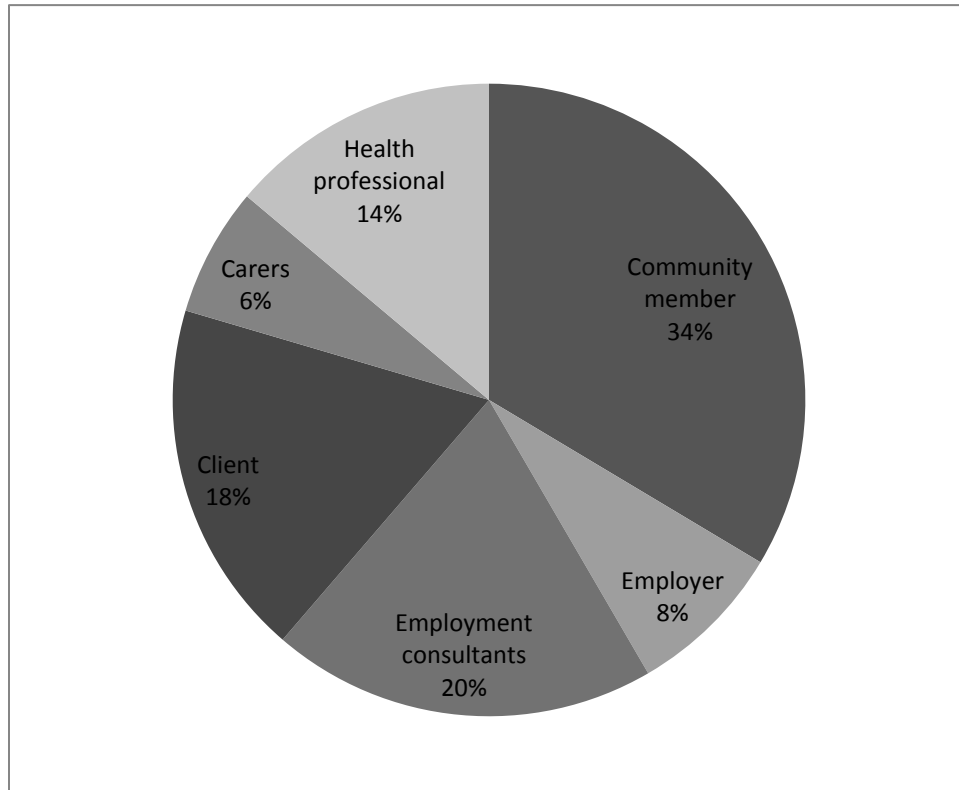
It was considered that groups consisting of people representing the same stakeholder group would allow more open and frank discussion on the topic. Each focus group comprised between three to ten participants identified as belonging to a particular stakeholder group. It soon became apparent, however, that many focus group participants represented more than one stakeholder group. Community focus groups included participants who were co-workers and government decision-makers. The number and composition of focus groups is shown in Table 1 and Figure 5.

Table 1

*Composition of Sample: Focus Groups and Interviews*

Stakeholder group	No. of focus groups	No. of group participants	No. of interviewees	Total participants
Clients	3	17	8	25
Carers	1	7	2	9
Employers	1	8	3	11
Employment consultants	3	24	3	27
Community members	5	41	5	46
Health professionals	1	9	10	19
Total	14	106	31	137

*Note.* One community member group was composed exclusively of young people aged 18-25 years while another consisted of representatives of community service organisations. It became evident during the course of groups that some participants were in fact representatives of multiple stakeholder groups.



*Figure 5.* Representation of stakeholder groups in sample.

***Focus group processes.*** Focus groups were held in private and public venues arranged with service providers and community organisations. All participants were unpaid volunteers and light refreshments were provided. All groups were facilitated by the researcher, who is a clinical psychologist. In accordance with research ethics committee requirements, a registered psychologist was also employed as a research assistant to attend all client focus groups. The purpose of the co-facilitator was to

exercise duty of care in the event of a participant requiring emotional support during the course of a focus group. An information sheet with the contact number for local mental health support services was also available to provide to any client should the need arise.

Prior to commencement of the focus group, information was provided on support available during and after the group. The following ground rules were explained and agreed upon:

- there is no pressure to say anything unless you wish to;
- you can leave the group at any time without consequence;
- respect each other's opinions;
- avoid cross-talk as far as possible to enable all views to be adequately recorded; and
- respect the confidentiality of other participants.

All groups ran for approximately one hour. All focus groups were asked to respond to the following two main statements/questions, with half the time allocated to addressing each question:

- Question 1: We know that many people who have been diagnosed with schizophrenia or bipolar disorder would like to work in regular paid employment. We also know that the employment rate of people with these conditions is significantly lower than the general population. Why do you think this is the case?
- Question 2: What do you think would need to change in order to improve employment outcomes for people who have been diagnosed with schizophrenia or bipolar disorder?

The role of the researcher was to facilitate discussion by group members. Open-ended probe questions were used if necessary to stimulate discussion and keep the discussion targeted. With the exception of the two main questions posed to the group, the facilitator adopted a non-directive style, using only minimal verbal and non-verbal encouragers. The discussion was recorded using two high sensitivity digital voice recorders.

Focus groups were arranged and conducted until a point of saturation was reached when no new themes were considered to be emerging (Wodak & Krzyzanowski, 2008). One carer who did not wish to participate in the carer focus group instead provided a written submission which was also included in the data set for analysis.

### **Stage 2-individual interviews.**

***Interview sample.*** Following completion of the focus groups, a purposive sample of in-depth individual interviews was conducted with representatives from each of the different stakeholder groups. A purposive sample of 31 interviewees was recruited from multiple sources and locations within the same geographical catchment area as the focus group participants. Interviewees included clients (6) and peer support workers (2) with lived experience of a psychotic condition. These included participants who disclosed a diagnosis of bipolar disorder (6), schizophrenia (1) and schizo-affective disorder (formerly diagnosed as schizophrenia) (1). Health professionals interviewed were psychiatrists (2), psychologists (5), an occupational therapist and a psychiatric nurse. The psychologists interviewed were employed in hospital, community mental health and private practice settings. Community interviewees included a politician lawyer (who was also a co-worker with a person diagnosed with a psychotic disorder) and teachers (3).

The sample included 11 male and 20 female interviewees. The age of interviewees ranged from 24-73 years with a mean of 50.5 years. The following criteria guided the recruitment of interviewees:

- individuals representing demographic characteristics significantly different from those represented in focus groups;
- individuals whose availability precluded their participation in a focus group;
- individuals identified as rich sources of data on the topic by virtue of their personal experiences;
- individuals identified as having experiences exceptional to the general trend and
- individuals in positions where they are able to significantly influence the behaviour and perceptions of others.

***Interview processes.*** Interviews were held in public venues including workplaces and private spaces in public libraries. The duration of the individual interviews was approximately one hour. With the exception of two interviewees, all interviews were conducted face-to-face. Skype was used to interview one client interviewee who had relocated during the period of the study but was nevertheless keen to participate, and a phone interview was used for an interview with a health professional to accommodate the participant's personal commitments. All interviews were audio-recorded using a digital voice recorder. Interview data-gathering continued until saturation point was reached, when no new ideas emerged.

### **Data Analysis**

Demographic information pertaining to each participant was recorded in NVivo 10. Participants in paid employment at the time of the study were classified according to

the major occupational categories of the Australian and New Zealand Standard Classification of Occupations of the Australian Bureau of Statistics (Australian Bureau of Statistics, 2013):

- Major Group 1 Managers.
- Major Group 2 Professionals.
- Major Group 3 Technicians and Trades Workers.
- Major Group 4 Community and Personal Service Workers.
- Major Group 5 Clerical and Administrative Workers.
- Major Group 6 Sales Workers.
- Major Group 7 Machinery Operators and Drivers.
- Major Group 8 Labourers.

The remaining participants were classified as students, retirees or “not in paid employment”. Participants who were “not in paid employment” included disability support pensioners and people performing voluntary or other types of unpaid work. It should be noted some participants had previously performed occupational roles which would have placed them in different occupational categories in terms of the above classification system. For example, one retiree identified himself as having previously been employed as a tradesman and salesman, which are roles classified in group 3 (Technicians and trade workers) and Group 6 (Sales Workers), respectively. These categories would appear to be under-represented in the current sample. The occupational classification of all participants in this study is shown in Figure 6.



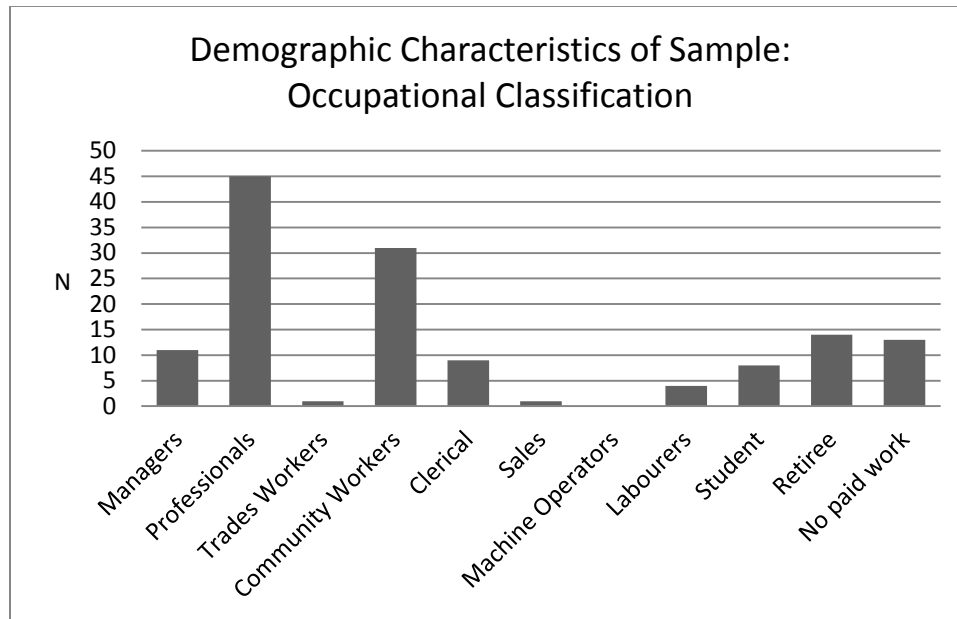


Figure 6. Demographic characteristics of sample: occupational status.

Audio recordings of focus groups and interviews were transcribed and imported into NVivo 10 software for purposes of coding and content analysis. The data gathered represents fourteen hours of focus group interaction and thirty one hours of individual interviews; a total of forty five hours of communication with respondents. NVivo 10 qualitative software was selected for use in this study as it allows the researcher to store, systematically explore and analyse large quantities of qualitative data. Transcripts were initially free coded into thematic nodes (categories), which were operationalised and progressively organised into a hierarchical structure representing the main employment barriers and support needs.

The contents of the most heavily coded nodes, representing the most commonly referenced barriers and support needs, were identified and described. This procedure is explained in more detail in the next chapter. Where appropriate, findings were illustrated with narrative quotes provided by participants. Exceptions and positive experiences were

also identified, where considered relevant. Visualisations of the data, in the form of tree maps, charts and models, were generated using NVivo 10 software to demonstrate salient findings. Themes that emerged from the data were used to develop a broad theoretical understanding of factors maintaining the status quo and to identify some possible future directions to improve employment outcomes.

### **Validity Considerations**

Several authors have emphasised the need for awareness of the potential impacts of the researcher on participant responses in qualitative studies, including the personal characteristics of the researcher (Maxwell, 2005; Barbour & Kitzinger, 2001). In terms of social interactionist theory, researchers form part of the social world they study and the data they collect (Charmaz, 2006). Characteristics of the researcher such as cultural background, age and social class inevitably affect what participants are willing to disclose in the research situation and what the researcher “sees” in the data. Roles and relationships may also influence the generation and interpretation of data in a qualitative study. In the current study, the impact of the researcher was minimised by maximising the role of participants, allowing groups and interviewees scope to self-direct the course of discussion as much as possible, and offering only minimal encouragers and prompts where needed to stay on topic. Following focus groups and interviews, time was taken to reflect and record memos on significant observations made by the researcher. There were no reportable incidents during this study. All groups and interviews ran for full duration and showed excellent engagement with the topic. Many participants appeared inspired and thankful at the opportunity to express their views on this topic.

Maxwell (2005) highlighted the importance of self-knowledge as a means to curb bias in the way a researcher views the data and suggests that reflective self-analysis constitutes an important means to improve validity of interpretation. Personal reflection formed an important component of this study, with relevant self-observations recorded in the form of memos. Reflection involved thoughtful consideration of personal reactions; unexpected reactions of organisations and participants, non-verbal behaviours, degree of engagement of participants, comments made immediately following groups or interviews and other contextual observations. This process was used as an aid to interpretation of the transcribed data and for purposes of framing further questions to be included in the further course of the study.

Coders were used to test inter-rater reliability and to assess the clarity of definitions of emerging nodes and the independence of node categories. Early in the analysis process, the researcher invited two research participants to code excerpts of transcript from the focus groups in which they had participated to check any need to clarify individual node descriptors and to measure the degree of inter-rater reliability. Coders were given a section of de-identified transcript, together with descriptions of six nodes representing the main identified employment barriers and support needs. They were provided with a set of highlighter pens and instructed to colour-code sections of the transcript corresponding to these six nodes. The resultant coding was entered into NVivo software and coding comparisons generated to determine the degree of consistency between participant and researcher coding. The coding comparisons revealed high levels of agreement between the researcher and co-raters in respect of all six nodes.

Other researchers were consulted for purposes of eliciting feedback on the face validity of the hierarchical coding structure. The use of NVivo 10 software provides transparency in relation to the coding decisions, enabling other researchers to replicate the decision-making process.

Maxwell (2005) suggests that respondent validation is the single most important way of ruling out the possibility of misinterpreting the meaning and perspectives of participants. This involves soliciting feedback from participants in the study concerning data and conclusions reached. The researcher was invited to present preliminary study findings of this study to a follow-up meeting arranged by one of the focus groups. For purposes of corroborating findings and testing the validity of interpretations and propositions, feedback on preliminary findings was provided to some participants, including participants with lived experience of psychosis. There were no findings that were contested by participants and further corroborative evidence was provided supporting the validity of the findings.

Sinkovics and Alfondi (2012) have emphasised the need to provide a searchable record for each stage of the research process. The use of computer assisted qualitative data analysis software generates a retrievable audit trail of all coding decisions and analyses, thus promoting transparency and strengthening the trustworthiness and credibility of the qualitative approach (Bazeley, 2013; Richards, 2002, Sinkovics & Alfonso, 2012).

## **Chapter 5: Application of NVivo Qualitative Software Technology**

NVivo 10 is a computer software package which is widely used for data analysis in qualitative research. Nvivo can be used as a tool to organise and manage data, and facilitate analysis irrespective of the theoretical perspective adopted by the researcher. The use of computer assisted qualitative data analysis software can greatly enhance the rigour and depth of analysis possible in a qualitative research project (Sincovic & Alfonso, 2012). This chapter explains the reasons for choosing NVivo software for this project and describes how its various functionalities were used. Technical proficiency in the application of this software was acquired through attendance at training workshops, webinars, individual consultations with experienced NVivo users and participation in the beta testing programs for NVivo 9 and NVivo 10. In addition to technical manuals, a number of other publications were consulted, which provided guidance on different approaches to using NVivo software in qualitative research projects (Bazeley 2009; Bazeley 2013, QSR International, 2010).

There are numerous computer assisted qualitative software tools available to researchers. NVivo 10 is one of the most popular and advanced qualitative research data software analysis tools currently available. It was selected due to its widespread use internationally and ready access to local training and support. NVivo 10 software is ideally suited to organise, store, analyse and share large quantities of qualitative data including audio files and transcripts from focus groups and interviews.

In contrast to manual coding methods, NVivo software provides a convenient, transparent and retrievable record of node hierarchies, content coding at nodes and coding decisions enabling other researchers to scrutinise and replicate the process. It

allows two or more users to collaborate on a project by independently coding content and storing memos and annotations, which can be viewed by co-researchers. It also allows comparison of coding performed by two or more researchers, generating results in the form of percentage agreement and kappa coefficients. The software automatically generates a project summary report showing the dates and times of all modifications made during the course of the project. In addition, the software enables node reports to be generated during the course of the project for review and discussion with co-researchers.

Unlike manual coding methods, NVivo allows portions of text to be coded and stored in multiple nodes. NVivo 10 advanced analysis tools include a variety of query options which facilitates rapid extraction of relevant information from large quantities of data. A text search query enables the researcher to rapidly locate and contextualise a particular word, phrase or concept in the project. A word frequency query function enables the researcher to determine the frequency with which specific words or phrases are used in the project. A range of coding query options allow rapid extraction of data stored at selected nodes, a combination of nodes or nodes with particular attribute values. Coding queries in NVivo 10 also allow the researcher to investigate hunches about the relationship between nodes by enabling extraction and exploration of content coded at multiple selected nodes. A matrix coding query option enables the researcher to determine the frequency of references coded to specific nodes across selected sub-groups of participants.

NVivo 10 provides a variety of visualisations of data to aid analysis, including coding density stripes, charts, tree maps, word frequency tag clouds, word trees, node hierarchies and reports. Coding matrices can be generated to compare the number of

references across nodes with different attributes values. Visual models showing parent and child nodes can also be rapidly generated from the data stored in the project.

The following minor limitations of NVivo 10 software were noted during this project:

1. Matrix coding results show frequency scores without regard for varying sample size of sub-groups represented in the matrix. Additional manual computation is therefore required in order to render frequency scores comparable across sub-groups of varying sample size.
2. Visual models generated by NVivo 10 must be manually adjusted to approximate the proportion of data represented by each component of the model.

The following stages describe the process used in applying NVivo 10 technology in this project.

### **Stage 1: Creating a Project ‘Shell’**

This stage involved creating the initial structure in which to store project details and data pertaining to sources and nodes. Folders were created for internal sources (focus groups, interviews and project diary) and memos. Folders were also created for nodes including people nodes (with sub-folders for focus group participants and interviewees), thematic nodes and relationship nodes. The screenshot below shows a list of memos created during the project.

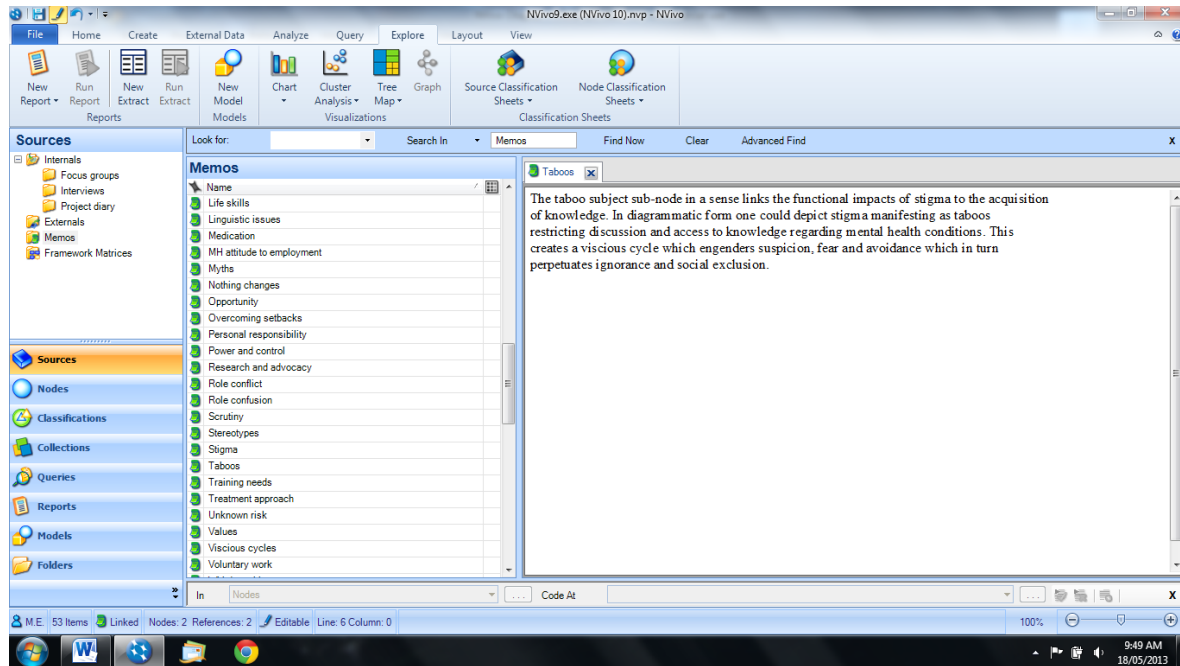


Figure 7. Screenshot of NVivo 10 showing source folders.

## Stage 2: Importing Data into the Project

This stage involved importing a spread sheet containing demographic characteristics of participants into the appropriate node classification folder. Transcripts of audio-recorded focus groups and interviews were also imported into the project and stored in the appropriate source folders.

## Stage 3: Classification of Sources and Participants

Attribute values were assigned to all data sources and participants to facilitate later in-depth analyses. Data sources were classified according to the mode of contact (i.e. focus groups or individual interviews). Participants were classified according to the attribute values as shown in screenshot below.



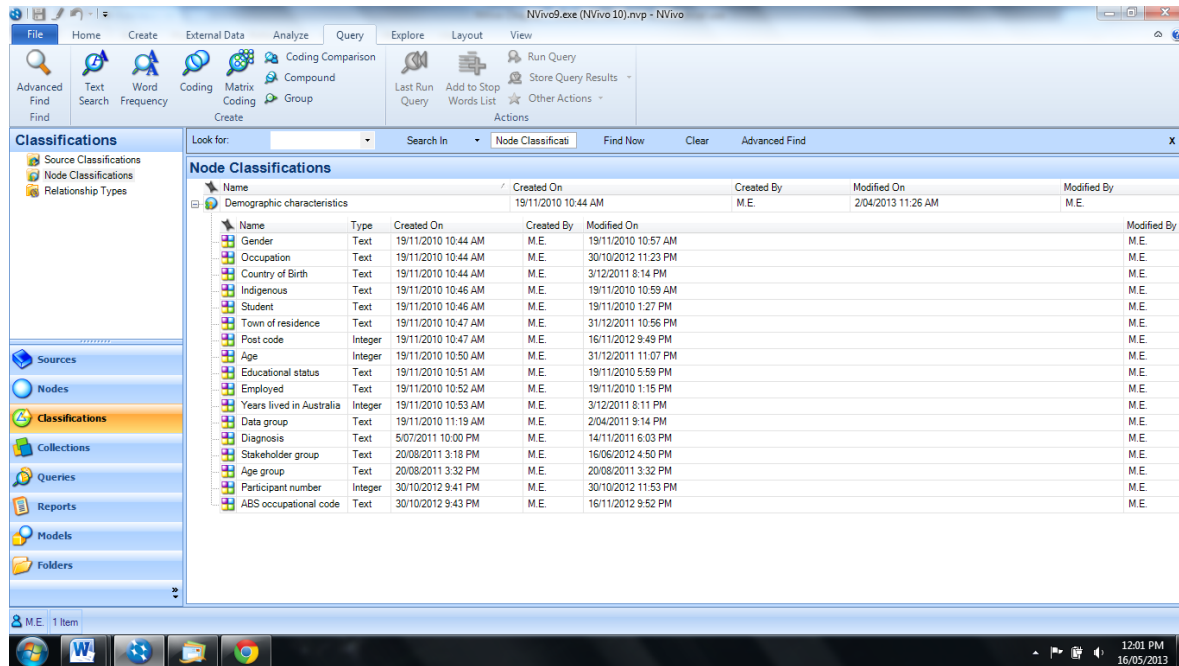


Figure 8. Screenshot showing attribute values assigned to people nodes.

#### Stage 4: Coding

This stage involved studying the transcripts to identify topics, ideas and concepts relevant to the research questions (employment barriers and support needs). Sections of text relevant to these concepts were coded and stored in thematic “nodes” (Bazely, 2009).

A node can be conceptualised as “A container that lets you gather source content relating to themes, people, places, organisations or other areas of interest” (QSR International, 2010, p.110). The purpose at this early stage of coding was to identify lower order themes. The principle adopted during this free coding stage was there is no wrong code. Each transcript was reviewed several times and at different stages during the project until the researcher was satisfied that all employment barriers and support needs had been adequately captured. Multiple coding was done where sections of text were relevant to multiple nodes. Coding stripes and highlighting features were used to facilitate the process of coding and reviewing previous coding. Notes on particular

sections of text were stored in the form of annotations. Observations, personal reflections and insights gained during the research process were stored in the project in the form of annotations and memos.

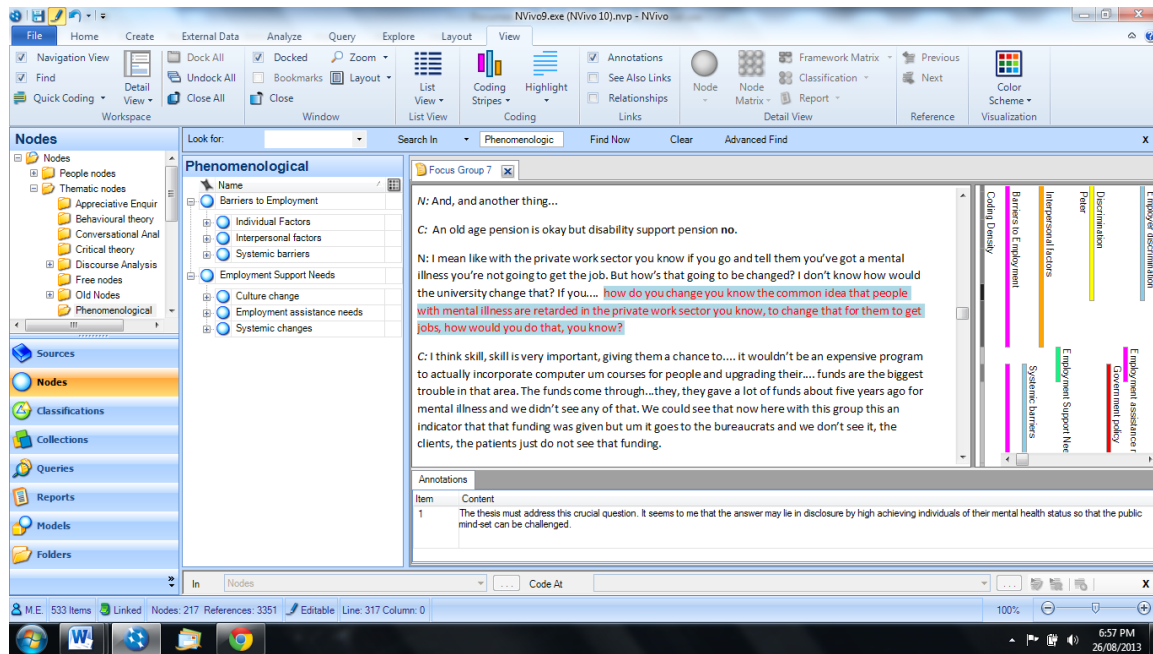


Figure 9. NVivo screenshot showing coding stripes and text annotations.

### Stage 5: Creation of a Node Hierarchy

This stage involved creating and defining new nodes (categories or constructs) and progressively organising the nodes into a hierarchical node structure comprising more general, higher order nodes (parent-nodes) and more specific sub-nodes (child-nodes). The guiding question in organising nodes into a hierarchical structure was “Is this node a sort of [a higher order node]?”. As the hierarchical node structure evolved, node definitions were refined, contents of existing nodes reviewed and transcripts revisited to ensure all relevant references were captured in the most appropriate nodes. This necessitated each transcript being reviewed several times at different stages in the analysis process. The node structure was progressively refined by reorganising nodes into

the most economical structure. The screenshot below shows the final node hierarchy consisting of six primary nodes.

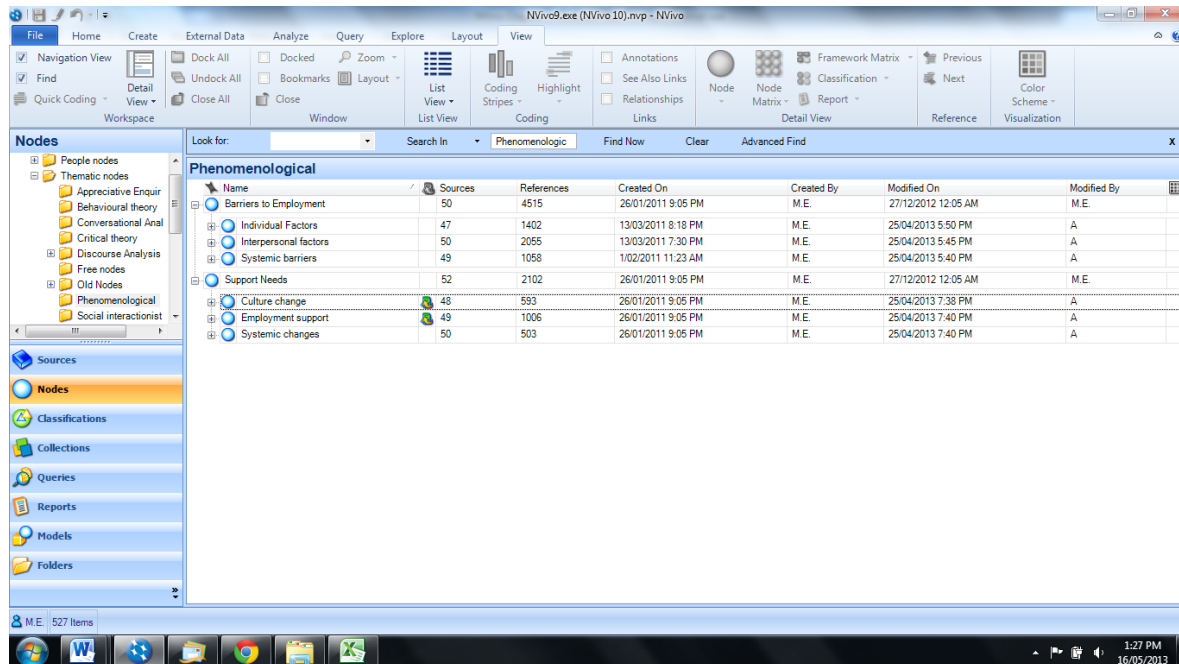


Figure 10. Screenshot showing hierarchical structure of primary nodes.

Once the main barrier and support nodes had been identified and defined, a validity check of coding was conducted by inviting two research participants to code excerpts of transcripts from the focus groups in which they had participated. Their coding was then compared with that of the researcher using the coding comparison query functionality in NVivo 10. The purpose of this comparison was to check inter-coder reliability against the primary nodes but more importantly to review and refine the node descriptors.

### Stage 6: In-Depth Analysis

This involved exploring and constantly interrogating the data using analytic tools in NVivo 10, including word search queries, word frequency queries and various types of coding queries. Results of all queries were stored in the project, making them available for later review and scrutiny. Matrix coding queries were useful for determining the

relative frequency of references to a particular topic by participants of different stakeholder groups. Advanced coding queries enabled extraction of references coded at multiple selected nodes, enabling the researcher to test emergent hypotheses about relationships between nodes. The screenshot below provides a record of queries that were run as well as a sample of a matrix coding enquiry, which shows the number of references to business risks by stakeholder group. The contents of the matrix cells is live, and double-clicking on the contents of cells in the matrix allows viewing of all relevant references, enabling further in-depth study of responses.

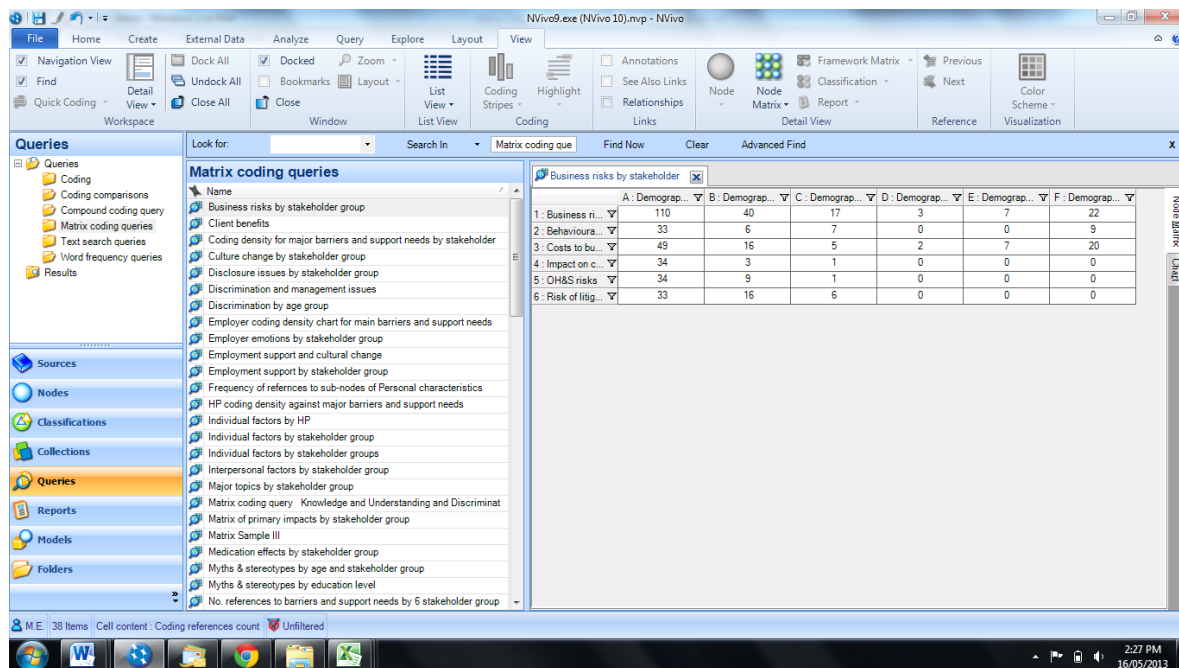


Figure 11. Screenshot showing matrix coding queries.

The software was able to generate visualisations in the form of node reports, charts, word clouds, word trees, tree maps and models. Node reports enabled viewing and discussion of the coding structure with supervisors and enabled easy identification of the most heavily coded nodes. The word cloud below reveals that the word “know” was the most frequently used word in the project.

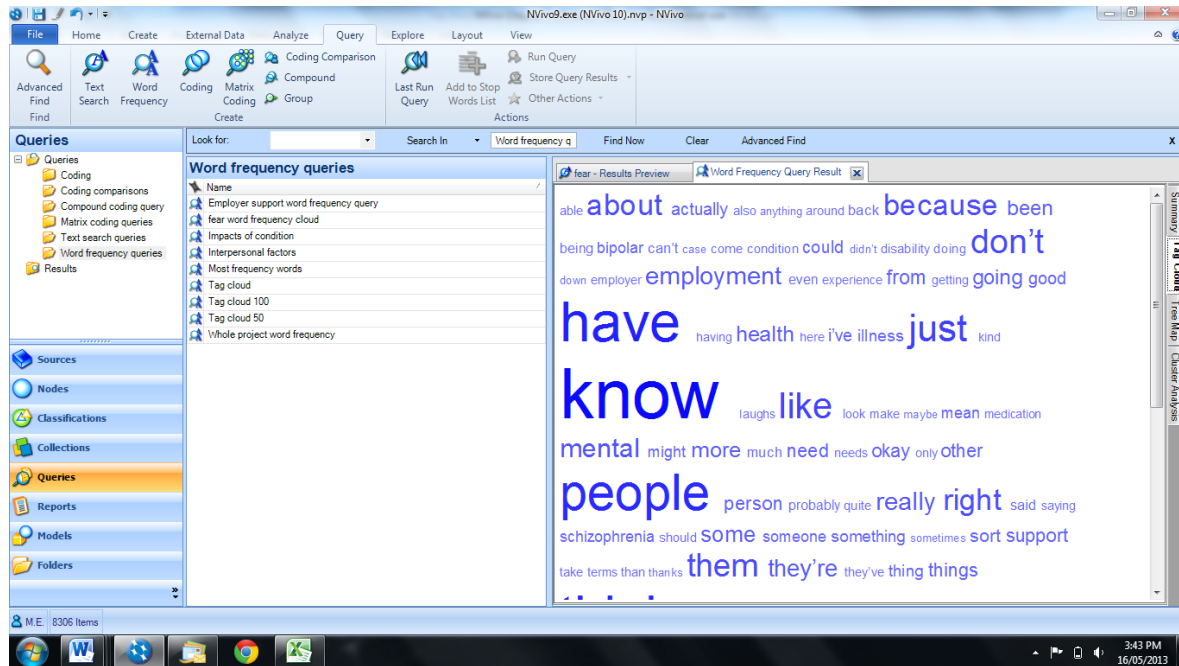


Figure 12. Screenshot showing word frequency query.

Word trees such as the one below enable the researcher to readily identify and access sections of text pertaining to the use of particular words or phrases by clicking on interactive links.

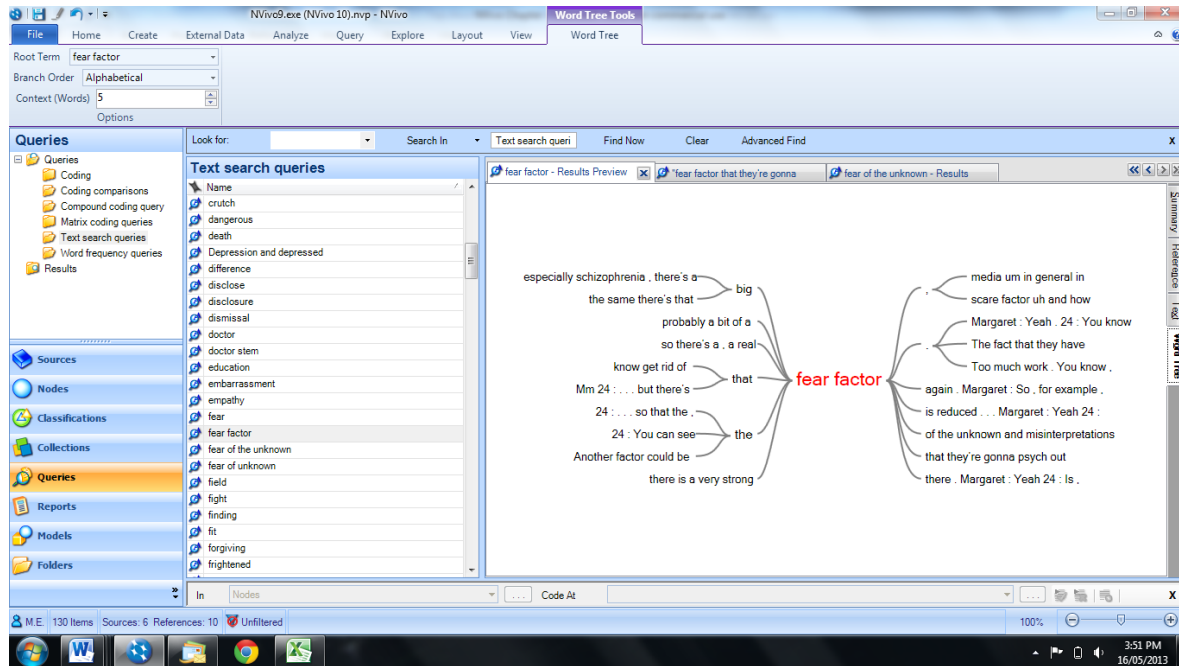


Figure 13. Screenshot showing a text search query.

During the analysis phase, the project was upgraded from NVivo 9 to NVivo 10, which provided greater storage capacity and faster processing of transactions.

### Stage 7: Reporting Results

The primary nodes and hierarchical node structure provided a useful framework in terms of which to report findings. The final node hierarchy was used to identify and report on the contents of the most heavily coded barrier and support nodes, which formed the main body of results. Salient results were demonstrated using visualisation functionalities including charts, tree maps and models. All visualisations can be exported from the software into word processing programs for reporting purposes.

### Stage 8: Integration of Findings

The final stage aimed to derive meaning from the findings by asking the question “What does all this mean?” Insights stored in NVivo in the form of memos and annotations were reviewed and integrated with results and literature findings to form an

in-depth understanding of employment barriers and support needs and draw robust conclusions.

## **PART B**

### **Results**



### **Overview of Findings**

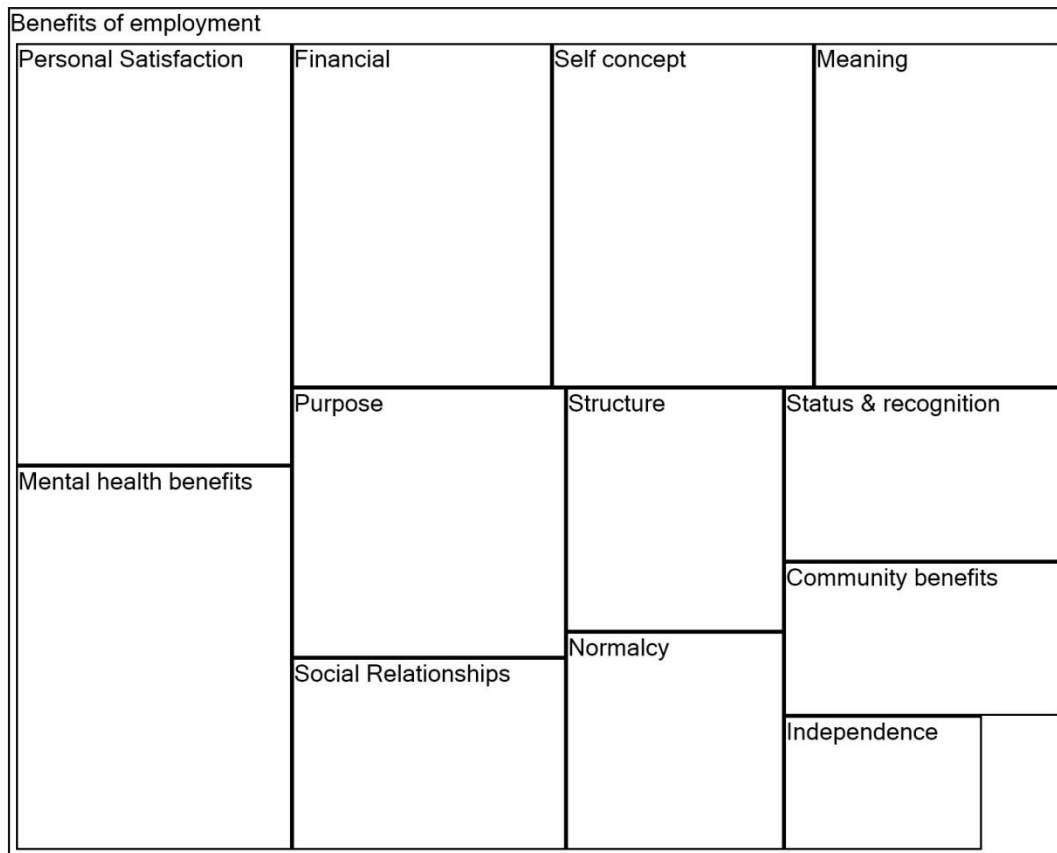
The results section comprises eight chapters, which use a variety of methods to report results. The first chapter focuses on respondents' views on the benefits and value of work for people living with psychosis. This chapter was included because it was apparent from the outset of this study that some key stakeholder groups seemed to be ambivalent about the importance of work for people recovering from a psychotic condition. Language plays an important role in conveying subjective experiences therefore the next chapter reports on three dominant metaphorical themes identified in the language used by participants: a combat theme, a sporting theme and a journey theme. The following three chapters focus on reporting on each of the main identified employment barriers: individual factors; interpersonal factors and systemic barriers. The next three chapters focus on reporting the results for each of the main identified support needs: culture change, employment support and systemic change. The focus in each of these chapters is on identifying, describing and visualising the most frequently coded barriers and support needs nodes within the node hierarchy. Some findings which were less frequent yet nonetheless deemed insightful and of potential value were also described. Where appropriate, charts have been provided to illustrate findings, and narratives included to corroborate and communicate the richness of the findings.

### **Chapter 6: The Importance and Value of Work in Recovery**

At an early stage in this research, it became apparent that representatives of some key stakeholder groups had significant reservations about whether employment is indeed a realistic goal for people living with psychosis, whether it is reasonable to expect them to work and whether it is in fact in their best interests to do so. For this reason it was considered important to include this chapter, which reports on participant views on the importance and value of work for people living with psychosis.

Several client participants in this study were successfully working in satisfying roles or were keen to obtain work. There were others who had been unable to find work or, due to their personal circumstances, had decided not to look for work. During the course of this study, participants expressed opinions on the importance and benefits of work for people living with psychotic experiences, either spontaneously or in response to probe questions. There was consensus that the benefits of work for a person with a serious mental health condition are the same as for anyone else in the community. The general consensus was that work has advantages for people living with a serious mental health condition, provided the work experience is positive and appropriate support is provided if needed. The benefits of work were categorised into the following themes: personal satisfaction; financial benefits; meaning; purpose; mental health benefits; structure, social relationships and self-concept. The tree map below (Figure 14) shows the proportion of references to each of the main categories of benefit.

Nodes compared by number of coding references



*Figure 14.* Tree map showing participant references to the benefits of employment. This tree map shows the proportion of references coded to each of the main benefit nodes (categories).

### **Personal Satisfaction**

Client participants expressed a sense of personal satisfaction, achievement and enjoyment associated with work. A peer support worker commented, "... it's nice, whether you're in a voluntary capacity or a paid capacity, to be doing something and it gives you that sense of worth and confidence and achievement within your life...." A child care worker with bipolar disorder said: "I love the fact that I can go in and I can teach them something..." A nurse with bipolar disorder said "I do feel that kindness to the

oldies is a very gratifying, satisfying thing...” while a part-time cleaner with bipolar disorder said “...cleaning it’s not really demanding, it’s a bit of fun and you start at about nine o’clock and finish at maybe twelve or one o’clock...”

### **Mental Health**

This theme incorporates references to the positive impacts of work on mental health and includes references to the activity, interaction and distraction that work provides. A medical practitioner recalled, “I used to have a patient who ran their own [business], did so for years...she had voices most of the day, worse at night when she got home...because she wasn’t distracted any more”. A psychiatrist similarly stated, “...in fact, a lot of people will tell me, ‘When I work those voices are less, I get distracted from the voices, that’s why I like my work’”. A client with schizoaffective disorder affirmed that “...the more time that I have by myself or the less interaction that I have with other people the more I end up thinking about the past or thinking about things too much”. The following statements by a psychiatrist also alludes to positive impacts of working on mental health:

The patients like working. They all really like working. Patients come in and they say they’re feeling good and you can see at the clinic they’re fine but when they start working it’s a different kind of thing. They’re more enthusiastic, more alive...they’re happy.

### **Financial**

This theme includes references to financial rewards associated with employment. One client respondent said, “... it’s really unfair the way they’re treating people and really

shutting them out from opportunities to earn money, make friends, have some sort of status in society ....” A psychologist contended:

...getting someone a real job, you know, so they can have real money and they can participate in society and get the things they want, same as anyone else...it’s probably one of the biggest issues to help people recover.

### **Self-concept**

Self-concept included references to self-identity, self-worth, self-esteem, self-efficacy, self-confidence and self-awareness. A client with schizophrenia observed, “...when you say I work at [supermarket] part-time...you’re just like everyone else. You know you’ve got an identity or whatever it is.” An employer alluded to impacts on self-confidence and self-worth:

...we’ve had feedback from quite a few of the boys’ parents...Christmas time is a time when they often come and see us and thank us and they themselves tell us what a huge change it’s made in their boys that is their self-confidence, their self-worth, their everything, you know, their whole outlook on life...

This employer also described the improved self-confidence she had observed in employees with schizophrenia as a result of employment: “When they come to us...they’re shy, they’re quiet, they’re nervous, and once they end up leaving our employ to go and pursue their own careers, the difference in them is incredible”.

### **Meaning**

This theme contains references to the role of work in providing a source of meaning in life. One client participant said, “...first of all, the sense of being useful...gives you a sense of meaning to wake up ” while another shared, “...I think that,

just the fact that I'm doing something...you know, I'm helping these kids to their start in life."

### **Purpose**

This theme incorporates references to work providing a sense of purpose in life. A client with bipolar disorder asserted:

...when I'm in work, I'm on top of the world. I have a lot going for me. I can see a future. I can see myself having children. I can see myself going overseas. I can see myself doing a lot of things. If I'm unemployed I don't see anything...

An employment consultant affirmed that "...as soon as you get somebody a meaningful job, it's amazing how things change, people change themselves because they have a reason to get out of bed..."

### **Structure**

This theme contains references to how work provides routine and structure. A client with schizoaffective disorder elaborated:

....the greatest thing that working does is gives me structure. I have to be at work at nine o'clock every day and that just makes the day so much easier because I know what I'm doing...I've got to have lunch at this particular time, I finish work at this time whereas now I wake up at any time of the day even though I've been told to wake up at eight o'clock, have your breakfast by then, this timetable sort of thing. It doesn't work if you don't have this force behind it...the structure is what I miss the most...

An employment consultant observed, “Even little things like...[the] weekend is [the] weekend when you’re working. When you’re not working every day rolls into another. There’s no high or low points.”

### **Social Relationships**

Work, whether paid or unpaid, was seen as an important aspect of overall social adjustment. Carers identified that it is “important to be seen in the general society as someone who’s contributing by working”; “it fits into society, into the box correctly”; and by working “they’re not going to look like they’re out of square, and they can just melt in with the rest”.

Employment consultants (according to participant number) also identified the importance of employment status in forming interpersonal relationships:

P69: ...even just in the social structure of life. What’s the first question you ask somebody you meet?

P63: Yes.

P62: Absolutely.

P69: So what do you do for a job?

P63: I don’t have a life.

P62: I’m on the pension, nobody wants to say that.

P63: So you’re already branded... “Ah I’ll go and get beer with somebody else then.”

P69: That’s exactly right. OK cool see you later.

A participant with schizophrenia observed, “...it’s the acceptance by others, the amount of respect by others that is given to you outside of the workforce. I found [when I was working] it was so easy to meet the opposite sex...”

Other benefits associated with working mentioned by participants were: the importance of work in normalising one's lifestyle; the status and personal recognition that comes from employment; the ability of the employed person to achieve independence, and positive impacts on the community.

Respondents indicated that the benefits of work may *not* be realised if there are adverse workplace management practices. For example, one respondent pointed out that a poor job-fit is unlikely to improve self-esteem.

Participants also referred to the disadvantages of employment and unemployment, and the advantages of *not* working. A summary of references to the costs and benefits of working versus not working is presented in Appendix I.



## **Chapter 7: Meaningful Metaphors**

Figures of speech used by participants provided insights into their subjective experiences of the barriers to employment and employment support needs of people living with psychosis. Analysis of metaphors used by participants revealed three major themes: a combat theme, an athletic theme and a journey theme.

### **Combat Theme**

In a metaphorical war against worklessness, some people were described as having “a bit more of a battle getting their condition stabilised”, others were “battling to get a job”, employment service providers “fighting battles” to stabilise jobseekers’ personal circumstances prior to being able to look for work, and a “big battle” was predicted against employer and public prejudice. Some people living with psychosis were perceived to have a comfortable relationship with their condition whilst others were seen to “fight” it. Non-acceptance of one’s mental health condition was perceived to be “fighting against all odds, against yourself.” There was reference to the “ongoing battle every day” for families of affected individuals and “ongoing battles” to change mind-sets in which “the front can change every day”. Carers asked how they are supposed to “keep fighting” to maintain their own sanity, health and relationships, and one participant observed that as a carer “you lose your life”. An employer expressed concerns about productivity in terms of the “brutal” arithmetic of employment. Inflexibility with work roles was perceived to be a “casualty” of modern employment. A supportive work environment was seen as essential to “survival” in employment. Employment providers sensed they were often treated like the “enemy” especially from government agencies.

There were many references to struggles including the “struggle in every single aspect” to obtain employment, having to “struggle continually” to maintain employment and the “struggle” with psychotic experiences even when regulated with medication. One client reported “it was always a struggle with the boss because he was an idiot and a tyrant”, the “struggle with the social situation of a workplace”; “struggling” to meet the opposite sex as a consequence of unemployment, and one respondent disclosed “being sick of the struggle”. Employment providers noted reluctance on the part of some providers to release relevant information, which was usually done under “sufferance”.

There were references to defence and retreat. Employers expected they may need to “defend” themselves against potential litigation. An employment consultant spoke about a discrepancy between the desire to work and the reality of work for people with long term “entrenched” mental illness. Some people work a limited number of hours and then “retreat” to a safe home situation. Others were perceived as reluctant to increase their hours because they like to retain their social security benefits in case they need to “fall back” on it.

There were also references to attack and munitions. Some suggested the government should “target” larger companies to provide employment opportunities for people with serious mental health conditions. A need was expressed to “capture” people prior to discharge from hospital and link them to employment support services as they may lack the initiative, confidence and social supports to access support services later. A health professional referred to the need for employers to be understanding when peoples’ circumstances were such that they were “under the gun”. Some clients were perceived to be “gun shy” as a result of negative work-related experiences. A psychiatrist described

work as a “double-edged sword”, stating that if individuals commence work before they are ready and it is stressful, they relapse. Employers described potential legal matters associated with employment of people with a psychotic condition as a legal “minefield”. It was felt that employers, when considering leave requests, may consider a person with schizophrenia to be a “loose cannon” compared to other employees. Teenagers and their peers were perceived to be “closed ranks” when it comes to disclosure of mental health issues to adults. Communication between people living with psychosis and peer support workers who have themselves had lived experience of psychosis was considered easier because “they’re on the same wavelength”.

### **Sports Metaphors**

There were also metaphors pertaining to a sports theme. Obstacles preventing people with psychosis from having equal opportunity of gaining and maintaining employment were often described as “hurdles”. The “first hurdle” was seen to be lack of self-belief, and the need for clients to believe they actually *can* work despite their condition. A carer, on the other hand, suggested the first hurdle is to find an empathetic employer who agrees to employ them. Another carer said that, particularly in the early stages, an enormous amount of home support was needed to facilitate work arrangements and help her son persevere when the work difficulties or “hurdles” came and he wanted to give up. She compared the level of carer support required at that time to that of an Olympic athlete. An employment consultant said privacy and the lack of being able to share relevant information is probably one of the “biggest hurdles”. Other issues described by participants as “hurdles” were restrictions to allowable hours of work and non-disclosure in the workplace.

There were several references to jumping. The transition from being in a psychiatric clinic to attending work was perceived to be “a huge jump”. A participant commented in relation to job pre-requisites, “they’re raising the bar higher and higher just to get a job”. It was also predicted a person with psychosis is likely to be “a terrifically willing worker because they can’t just jump from job to job”. Co-workers who are aware and understand that a person is working to their capacity may even be willing to “jump” in to assist if necessary.

There were many gymnastic expressions used by participants. It was felt that able-bodied employees may consider employers to be “bending over backwards” to accommodate co-workers with psychiatric disabilities, while non-disclosure seemed to result in employees having to “bend over backwards” to prove they are as good as everyone else. Balancing income from employment with potential loss of social security entitlements was seen as a “balancing act” that people with a mental illness do not need. An employment consultant cautioned there was a “fine balance” in providing an optimum amount of contact with an employer.

There were also many references to ball sports. The sense of financial security from being on a disability support pension was described as being “on a good wicket”. Overcoming social withdrawal to face the challenges of social participation was described as “stepping up to the crease”. An employment consultant commented that, “disclosure around those [psychotic] conditions is always really difficult and touchy...we don’t ever want to use clinical terms because the employers automatically *go on that back foot*.”

Another employment consultant suggested “in an ideal world, somebody would *throw* some serious money at training”. A community member challenged the stereotype of unreliability by commenting employees *without* mental health conditions “chuck sickies right, left and centre all over the place.” People who have finished their hospital treatment were perceived to be “thrown” back into the community instead of having a graduated return to the community. A client participant recalled one job agency that “just wanted to *throw* [people] in any old job”. A carer described as “a little throw in”, an observation that employers retain people without mental illness who are supposedly trained, and yet lack communication and other skills necessary to perform the work. An employer asked whether a person who just “lobbed” through the door could be dismissed if it was later discovered he has a mental health condition. Assisting people with a mental illness to find work was described as “like a whole new ball game” compared to assisting a person with a physical disability.

A participant with lived experience of bipolar disorder contended employees of affirmative businesses would have more co-worker support as they have “each other to bounce off”. A tertiary student with schizoaffective disorder considered it would be helpful to “touch base” with a more senior student in a particular subject area. An employment consultant suggested that post-employment support would consist of someone “touching base with them” following employment. Being out of the workforce for too long was perceived to mean “you’re gonna [sic] have to start back at bases again”. There was discussion of the work-related impacts of side-effects of medication used to “tackle” psychotic symptoms. Social exclusion was described as being “sidelined”. An employee suspected his employer may have thought he was “playing” him when a

promised wage subsidy did not materialise. One participant envisaged that other people would learn to become better “team players” if the workforce were more inclusive.

Participants used athletic terms to refer to the pace of activities and outcomes. Some people can “swim through” the system and make the transition from disempowerment to empowerment much faster than others, who need more time and resources to effect the transition. One client, who was ostensibly turned down after a period of work experience for being too slow, considered this was just an excuse as she had not been informed “there was a race on” to complete the assigned tasks. A carer felt more education was needed and did not foresee any rush to the “finish line” occurring in her life time. Some people were perceived to be resilient and trying extremely hard to secure work, whilst others were ready to “throw in the towel” very early. One client stated “I refused to let it [bipolar disorder] beat me” and indicated that she pushed herself to stay in employment “cause I know normalcy is what will make me better”. It was suggested that if employers had a good incentive to employ people who are capable and want to work “everyone wins”.

### **The Journey Theme**

The metaphor of a journey was another common theme. One client participant living with schizophrenia, said “...it’s not always easy...it’s actually a journey that you’re going through”... [you have to] stick with it...persevere...’cause at the end of the day I’ve had a pretty amazing life, meeting the people I have for my mental illness.” The journey was also described as a “lonely hard road”. A client with bipolar disorder said people were “very much out there in the cold” due to unawareness of employment support services.

A family member, in discussing the struggles of people living with psychosis, challenged others to “walk in their shoes a little bit”. Peer support workers could reassure service users that “we’ve been in your shoes so you don’t have to be quite so afraid.” A client with bipolar disorder said his psychiatrist and general practitioner ask about work but as long as he is “plodding along reasonably”, “the conversation doesn’t go too far”. A psychiatrist suggested “the patient leads you” in regard to their capacity to cope with work-related stress. When people with psychosis are involved in incidents of violence, “the mud sticks” and affects employers’ unwillingness to employ people with these conditions. A rehabilitation counsellor explained that people with a long term mental health condition may think the idea of working is very attractive but lack motivation “to take the next step”. Medication, it was suggested, can “become a walking stick” while some may use mental illness as a “crutch” to avoid doing anything or for doing less. People discharged from a psychiatric clinic were seen to need a “crutch agency” they can lean on.

From an employment service provider’s perspective non-disclosure was likened to “pedalling backwards”. It was envisaged that non-disclosure of a mental health condition in the workplace could also lead to “coming unstuck down the track”. A person receiving anti-psychotic injections was described as “super-charged” following an injection and “like a car with a flat battery” when the next injection was due. A client with bipolar disorder cautioned against jobs with very long hours or that impede the ability to “re-charge”. An employer claimed his organisation was not “geared up” to support employees working with schizophrenia or bipolar disorder. The employment of more people with serious mental illness was seen as the best form of community

education, although it would need to be well managed, otherwise it could “backfire” if there are bad experiences. Others expressed a need to put on “brakes” at times to avoid detrimental outcomes. A carer expressed a need for carer education, including awareness of employment and other resources, but did not expect significant change to occur in her life time and predicted that the “wheel will turn slowly.” She said that “thirty five years down the track” she was still waiting for change. Carers viewed a recovery plan from the outset of treatment as essential to “get your life *back on track*”, put the person on a “pathway” to quality of life, and demonstrate that there is “light at the end of the tunnel”. Some employers who have had a bad experience employing a person with mental illness reportedly said they had “been down that track” and may be unwilling to try again.

There were many vicissitudes on the journey to find employment. A psychiatrist stated that work stresses some people out and their condition goes “downhill”. Some people “fall off the horse” after experiencing workplace prejudice. Relapses were described as “going off the rails”. The unemployed may “fall into the trap” where they see no reason to get out of bed in the morning. The long-term unemployed can “fall into a trap” where they lose motivation to seek work. An employer described his experience of employing a person with bipolar disorder as “stamping out fires all over the place” while a client recalled being “pulled over the fire” by his employer for using self-stigmatising humour. Carers described employees with psychosis finding themselves “lost” in situations requiring informal social interaction with co-workers. One participant who was succeeding in employment acknowledged the support of her partner and her partner’s family, without which she would be “lost”. She also stated that knowing she had the support of her partner’s family “keeps me on the straight and narrow”. A person who had



successfully completed a number of transitional employment placements protested that “it leads to nothing” as they lost the work at the end of the placement through no personal fault. People with mental illness who do not work often lack activity to “transport them away” from stressful symptoms, even for a brief while. Communication, honesty and trust between employment consultant, employer and employee was described as a “three way street.” There were many hindrances and obstacles along the way, which were described as “stumbling blocks”, including lack of confidence in their ability to work, long-term unemployment and fixed ideas in the community. Employment opportunities were frequently described as “stepping stones”.

There were also many references to doors. Unfair exclusion from employment opportunities was described as “shutting them out” from opportunities to earn money, making friends, and having some sort of status in society. It was expected that a more positive community attitude would “open doors” to employment. Inept disclosure to a prospective employer was likened to “closing the door before it’s opened.” A therapist described people coming in and out of the “revolving door” of the hospital “because they haven’t quite found what it is that maybe they might be useful at or be or become”. Participants advocated for “making sure the doors are all open” to access employment opportunities rather than “shoving them through doors”, which referred to coerced participation.

The experience of stigma in the work environment was likened to entering a building site and needing to “put your hard hat on”. Loss of disability entitlements if working hours were increased was experienced as “being between a rock and a hard stone [sic]”. Job-seeking was described as “wasting my time banging my head up a brick wall”

while negative work-related experiences were similarly described as “a lot of head against the wall”. Making enquiries of government agencies was likened to “hitting brick walls all the way” and in relation to carers it was said, “they all seem to hit the same kind of wall”, referring to lack of outcomes when supporting people who want to and are looking for work. One employer described her employees with schizophrenia as “just normal guys just trying to get through life, you know, and they’ve been thrown some um some hard knocks along their way”. Many people reportedly wanted to “by-pass” disclosure altogether by remaining on the pension and avoiding any social interactions that may result in disclosure of their condition.

There were also many nautical idioms pertaining to a sea voyage. Diagnosis was described as “the first port of call”. There were 29 references to being “on board”. A psychiatrist indicated employers need to be “fully on board”. Participants considered that to have employers “fully on board” it would be essential to overcome employer ignorance, fear and prejudice. Peer workers with lived experience of psychosis were described as having come “on board”. An employment consultant, referring to the need for communication and collaboration between stakeholders, said that to be successful “you need everyone on board”. When a jobseeker “comes on board” it takes time for employment agents to get to know them and what they can manage. Carers talked about “getting someone on board” to engage people in volunteer work, and the need for more productive people and to turn the economy around by “pulling on board people and be tolerant of their levels of ability.” A private psychologist thought most psychologists would be “on board” if they were funded to provide work-focused psychological services to promote employment outcomes among people living with psychotic conditions. A

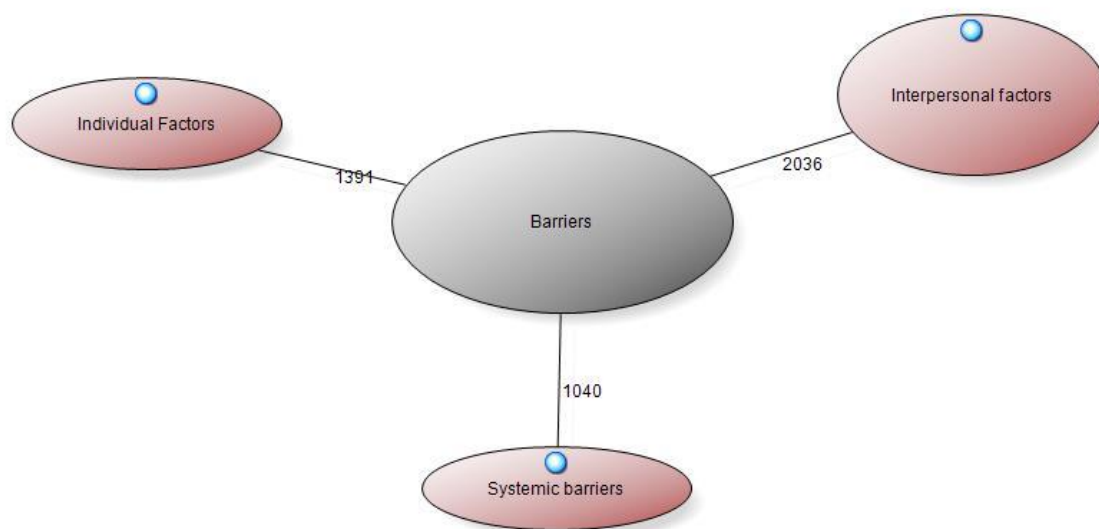
client participant commented that from an employer's perspective it was not like having a normal full-time employee and the experience can be "a little bit choppy" sometimes. Employers were perceived as becoming increasingly less sympathetic of inability to meet timeframes or need for absences from work due to feeling unwell, and more likely to adopt an attitude of "ship on or ship out". Social firms were perceived to provide more "leeway" than competitive employment situations for people with psychosis, in terms of understanding and flexibility in accommodating non-conforming behaviour. An employer indicated an employee with psychosis would need to be able to "pull their weight" in terms of the group (to use the nautical idiom). Another participant indicated that co-workers would also need to "pull [their] weight" and help out to compensate a colleague during a period of incapacity. Employers were seen to be unwilling to "cut as much slack" in relation to work absences as they do for other workers who may have lesser reasons for not attending work.

It was felt that employees of a business that affirmatively employs people with mental health conditions would find it much easier because their employers would have a better understanding and "know where they're coming from". A client participant thought employers would benefit from the opportunity to attend support groups to learn "where we are going from or what angle we're coming from". An employer said there was a need for employers to "speak to people who have been there", referring to other employers who have employed workers with psychotic conditions. An employment consultant stated employers, rather than taking "take the easy way out", should keep an open mind and employ people with mental health conditions. A participant with lived experience felt that

if others were “a little bit angry and political” in articulating their needs this “would go a real long way”.

### Overview of Employment Barriers

This section reports on results obtained across the combined sample representing all stakeholder groups (N=137). The most frequently referenced barriers to employment for people living with psychosis could be broadly categorised as individual factors, interpersonal factors and systemic factors. Figure 15 shows the frequency of coding references for all participants in the study against each of these barriers.



*Figure 15.* Diagram showing overview of main barriers to employment.

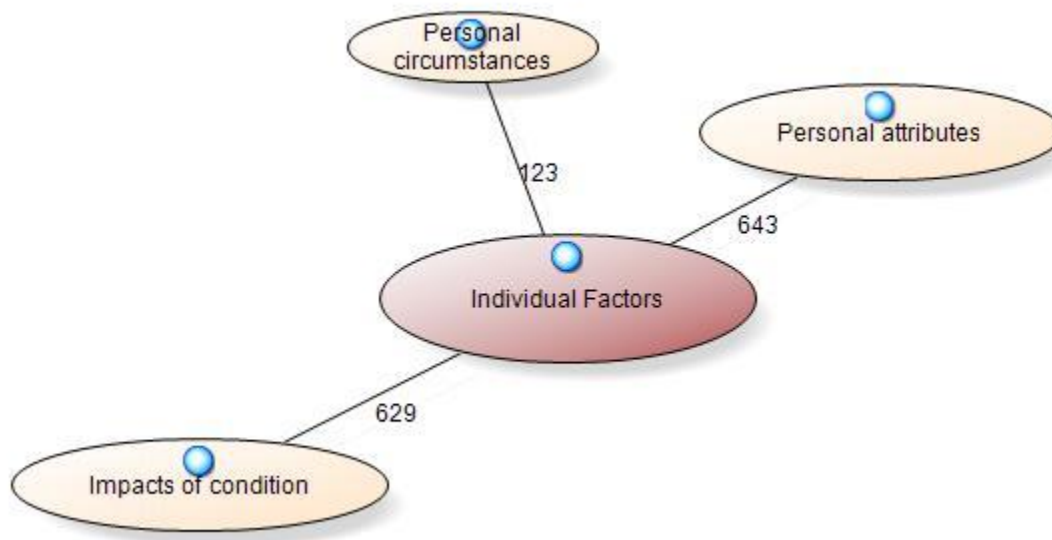
As can be seen from the above figure, interpersonal factors were the most commonly cited barriers identified in this study.

The following three chapters (Chapters 8-10) will provide a detailed discussion of findings in relation to each of the three main barriers: individual factors, interpersonal factors and systemic barriers. Each chapter will focus on describing the contents of the most heavily coded barrier nodes and will also include some less frequently referenced ideas deemed to be particularly interesting, insightful or useful. Findings will be

illustrated with narratives from participants and visualisations of the data. The results of in-depth analyses exploring relationships between nodes will also be reported. Some differences among stakeholder groups in their perception of barriers will also be presented.

## Chapter 8: Individual Factors

Individual factors were defined as barriers pertaining to the individual living with psychosis, and refers to the impacts of the condition, personal attributes and personal circumstances. As can be seen in Figure 16 below, personal attributes were the most frequently referenced individual barriers, followed by impacts of the condition and personal circumstances.



*Figure 16.* Summary model of individual factors as barriers to employment. The numbers adjacent to connector lines represent the number of participant references to each of the main individual barrier.

A more detailed analysis of individual factors as barriers to employment is provided in Figure 17. This chapter will focus on description of the contents of the most heavily populated individual barrier nodes.

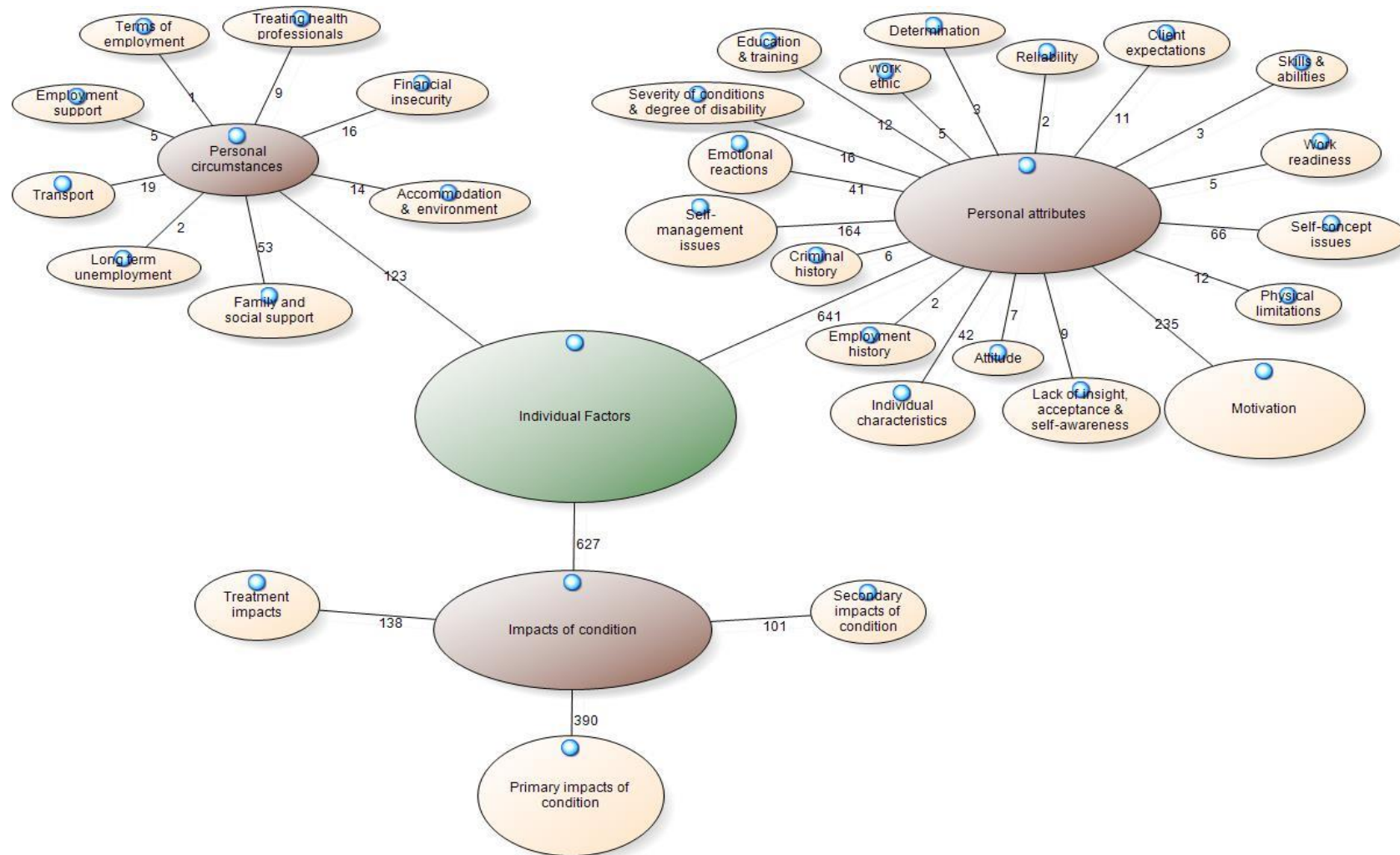
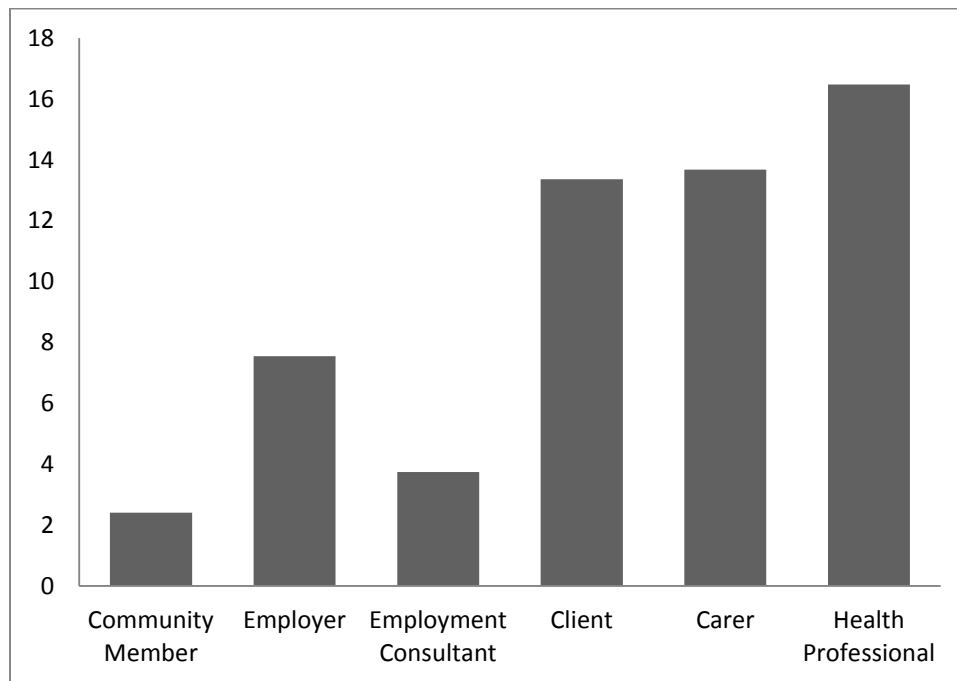


Figure 17. Second order analysis of individual factors as barriers to employment.



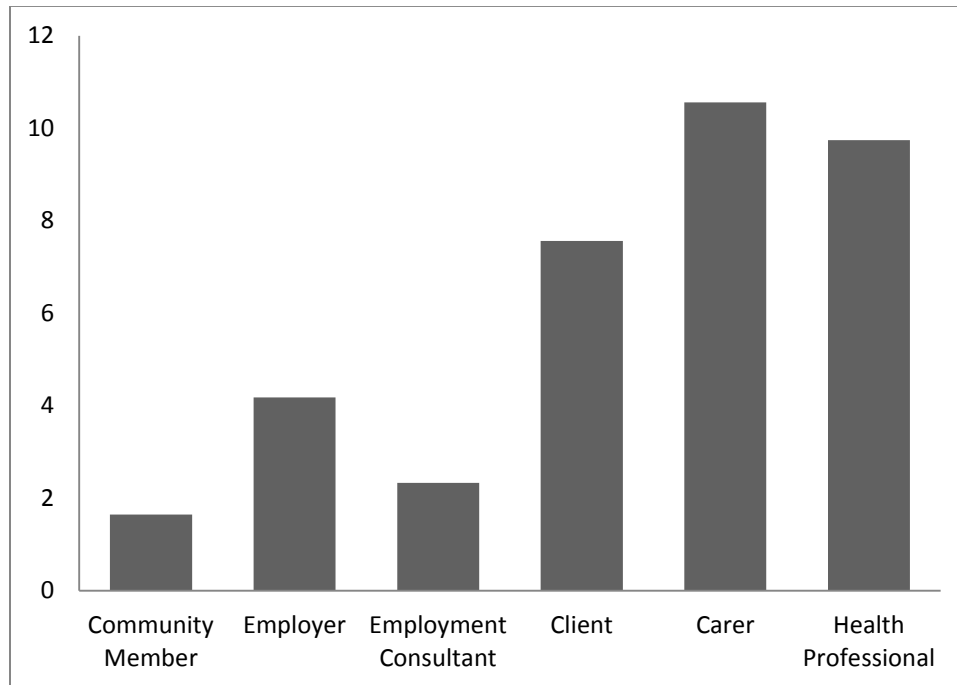
### Impacts of Condition

Direct impacts of the condition were perhaps among the most readily identifiable barriers and some respondents initially seemed to imply that there was no need to look beyond these factors to explain the low employment rate among people living with psychosis. Figure 18 shows the average number of coding references to impacts of the condition according to stakeholder group.



*Figure 18.* Average number of coding references to impacts of condition according to stakeholder group.

**Primary impacts of condition.** Respondents described wide-ranging impacts of these conditions on the ability to work. There were differences between stakeholder groups in terms of the importance attributed to primary impacts of the mental health condition itself as a barrier to employment (see Figure 19).



*Figure 19.* Average number of coding references to primary impacts of condition according to stakeholder group.

Carers made relatively more references to the primary impacts of the mental health condition on ability to work than any other stakeholder group, followed by health professionals and then clients. Carers made the most reference to social interaction, episodic fluctuations and stress tolerance. One carer commented on the stress associated with lack of self-confidence. The primary impacts of the condition most commonly referred to by health professionals were cognitive deficits, episodic fluctuations and social interaction. Primary impacts most commonly raised by clients were episodic fluctuations, social interaction and mood disturbance. Interestingly, however, no client participant in this study attributed unemployment primarily to the condition itself. Employers referred most frequently to the nature and severity of the condition, episodic fluctuations, and behavioural issues. Employment consultants referred most frequently to

the nature and severity of the condition, social interaction and episodic fluctuations.

Community members referred most frequently to social interaction, episodic fluctuations and mood disturbance. Overall, the primary impacts most frequently identified as barriers to employment were the episodic nature of these conditions, difficulties with social interaction, mood disturbance and cognitive impacts.

***Episodic fluctuations.*** Participants described inability to function in a job situation due to depressive or psychotic episodes. It was recognised that the duration of episodic fluctuations could be weeks to months and that this could have a significant impact on both employer and co-workers. Impaired judgement and inappropriate behaviour in the workplace were seen to result in embarrassment about returning to a previous work situation following relapse.

***Social interaction.*** Participants also referred to lack of social skills and a tendency for people with psychosis to isolate themselves for prolonged periods of time from interaction with others. Some participants attributed social withdrawal to factors other than the condition itself, such as lack of self-confidence and fear of social stigma.

***Cognitive changes.*** The most commonly referenced cognitive impact was concentration, which was perceived to potentially result in work errors. Participants also identified that there may be interference with the clarity and flow of thought, as well as disruption of creative thought. Other cognitive impacts observed were adverse effects on attention, executive functioning, organising, planning, sequencing, prioritising, decision-making, problem-solving, memory function, communication, and interference with new learning. Reduction in manual dexterity and processing speed were also noted. In

addition, participants identified that negative thinking styles may influence motivation and behaviour.

Health professionals, in particular, were concerned about the impact of cognitive factors on employment. There were, however, participants with schizophrenia who strongly challenged the view that cognitive decline is inevitable, one commenting, “it’s not like you lose any of your intelligence after going through the process.” One carer specifically pointed out that her caree with a diagnosis of schizophrenia has good problem-solving skills.

**Secondary impacts of condition.** Secondary impacts deemed to constitute barriers to employment included co-morbid conditions, career disruption, social stigma and loss of self-confidence. Respondents also referred to the anticipatory stress of becoming unwell again.

**Comorbidities.** The most commonly identified co-morbidity was substance misuse. A health professional suggested that high unemployment among people living with a psychotic disorder may be more attributable to the impacts of substance misuse than the mental health condition itself:

...when I’m thinking about the people that I’ve known who’ve had the mental illness and the people I’ve known that have been completely dysfunctional with it, the ones who are not functioning are the ones who are abusing something....(Psychologist)

Participants also mentioned the work-related impacts of other co-morbid mental and physical health problems.

***Career disruption.*** In general, serious mental health conditions were reported to disrupt education and result in gaps in a person's resumé and lower level work opportunities. Difficulties completing education and training, loss of employment and long term unemployment were considered other secondary consequences. Due to interrupted education, many people living with psychosis may find themselves working in jobs mismatched to their ability, and in work situations that are less likely to have a positive impact on mental health. Medication requirements and uncertain potential for relapse may further restrict employment choices. A carer described the negative impact on career trajectory, pointing out that employers may presume that a person has lost the skills and abilities they had prior to the condition's onset, and prior training may not be recognised.

Several participants commented on the effects of long term unemployment on sense of self, lifestyle and work conditioning. A health professional suggested that the longer a person has been unemployed the less likely they would be to change their lifestyle:

...when somebody has spent many years on a disability pension and just sort of swanned around the local shopping centre or whatever it is that they do... to expect them to be in full-time or even part-time actual open, competitive employment...I think it would be somewhat of a shock to the system.

(Psychologist)

***Other consequences.*** The uncertain aetiology of psychosis appears to be a barrier to acceptance of these conditions. An employment consultant expressed the opinion that employers would be more sympathetic if they understood that a disorder was due to

trauma, and that “it doesn’t sound as bad as if someone has had it all their life.” The less visible nature of psychotic conditions compared to physical disabilities was seen to impact on community understanding of the conditions and to have important work-related consequences. A carer commented: “If you had a physical one [condition] that everybody was aware of you’d get, ‘Ah, go and help so and so over there. They need a bit of assistance’ ...and it’s been like that for years.” Participants agreed that, in general, physical conditions elicit more understanding and acceptance in the workplace than mental health conditions. This was attributed to the less visible nature of the condition:

...if all of ours’ had bandages around their heads people would be... “Oh sit down” or whatever, you know, something’s wrong...it is true though, isn’t it, people can see that you’ve broken something...but when your brain’s broken... (Carer)

The secondary impact of social stigma on self-identity was also noted:

With mental illness, they take the illness and make it the whole person. They don’t usually do that with a physical illness. They don’t usually take someone who’s got some small physical illness that they’re treated for and suddenly .their whole life is about that [the illness]...but the stigma makes people think that if you’ve got a mental illness that’s all you are.... (Peer support worker)

The illness itself was seen to result in loss of self-confidence. In addition, the secondary impacts of stigma and discrimination on self-esteem and motivation were widely recognised by participants. The compounding impact of unemployment was captured in this statement by a peer support worker: “I found that the more that I was out of work the more that I lost a sense of self...”

Secondary stressors were perceived to develop around the condition including significant stress of becoming unwell and stress surrounding disclosure issues. One client reported that he had to curb his sense of humour, as joking comments about his diagnosis were not well received by health professionals with whom he worked, and met with severe sanction from his employer.

Other secondary impacts mentioned were disruption of social networks, loss of supportive relationships including family, friends and close personal relationships as well as difficulty forming new friendships. Participants mentioned that, because schizophrenia is such a difficult condition for families to live with, people may lose family support, become isolated and often homeless as a secondary consequence of the condition. It was felt that behaviour arising from uncontrolled symptoms could also lead to personal embarrassment or remorse, physical disfigurement, driving and other offences, potential risks to personal and community safety and result in a criminal record.

Participants identified similarities and differences between schizophrenia and bipolar disorder in terms of impact on ability to work. Self-confidence was considered to be affected in both groups. Some participants considered people with schizophrenia less employable and the condition more difficult to manage than bipolar disorder, with more severe impacts on cognitive functioning, higher stigma attached to it and more impacts associated with medication. Bipolar disorder was seen to result in more subtle work-related difficulties such as over-estimating one's work capacity.

**Treatment impacts.** Participants identified negative impacts of delayed diagnosis including misunderstanding of behavioural issues, substance misuse, and consequent strain on family and other social relationships. A carer participant identified the loss of

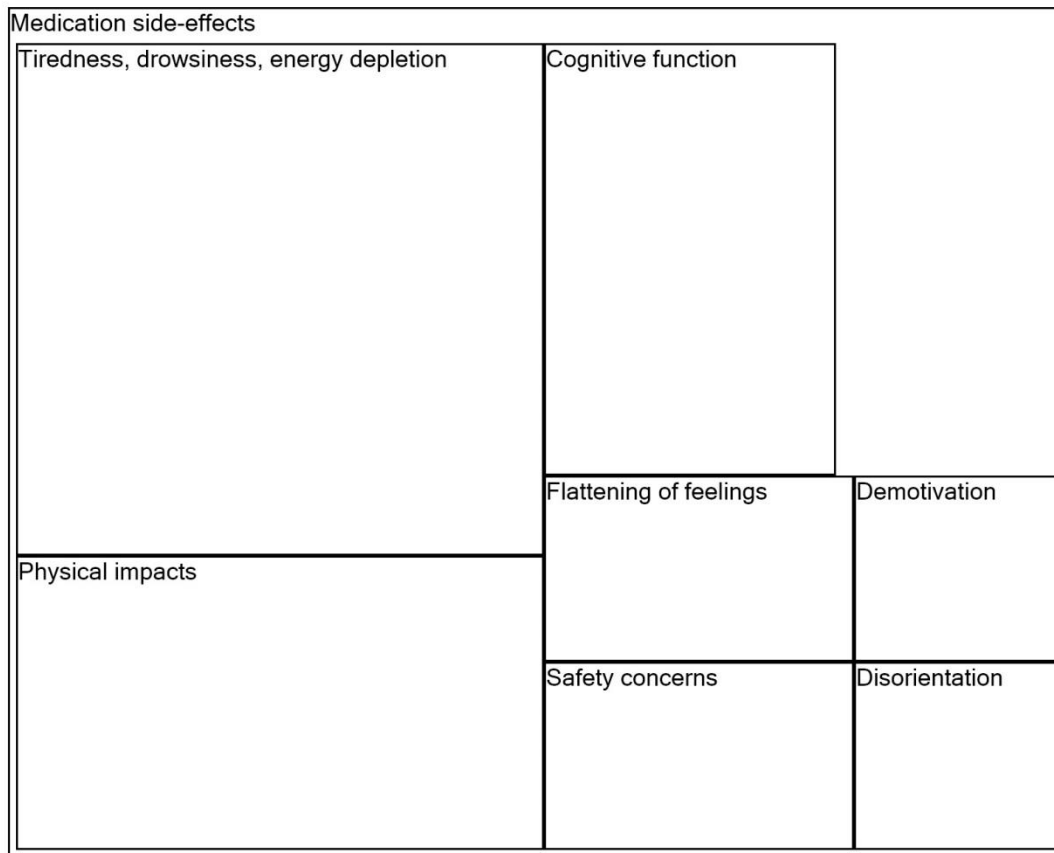
self-confidence related to the way clinicians, carers and society in general tend to take away the sense of personal control during the initial phase of treatment for psychotic conditions. Several respondents remarked that even those who comply with treatment experience ongoing symptoms of the condition. The efficacy of treatment was also cited as a potential barrier as well as side-effects of medication. There were references to people who were effectively medicated and working while others indicated that treatment itself can constitute a significant barrier to employment:

I did [hear voices] for three weeks at one stage so I realise how serious the problem is of hearing voices and also I've known people who hear voices and I think the medication is what's stopping those people from working. (Client)

An employment consultant shared, "...they [people living with psychosis] say the medication makes you feel worse than the actual illness". References by all participants to the impacts of medication side-effects on ability to work are shown in Figure 20.



Nodes compared by number of coding references

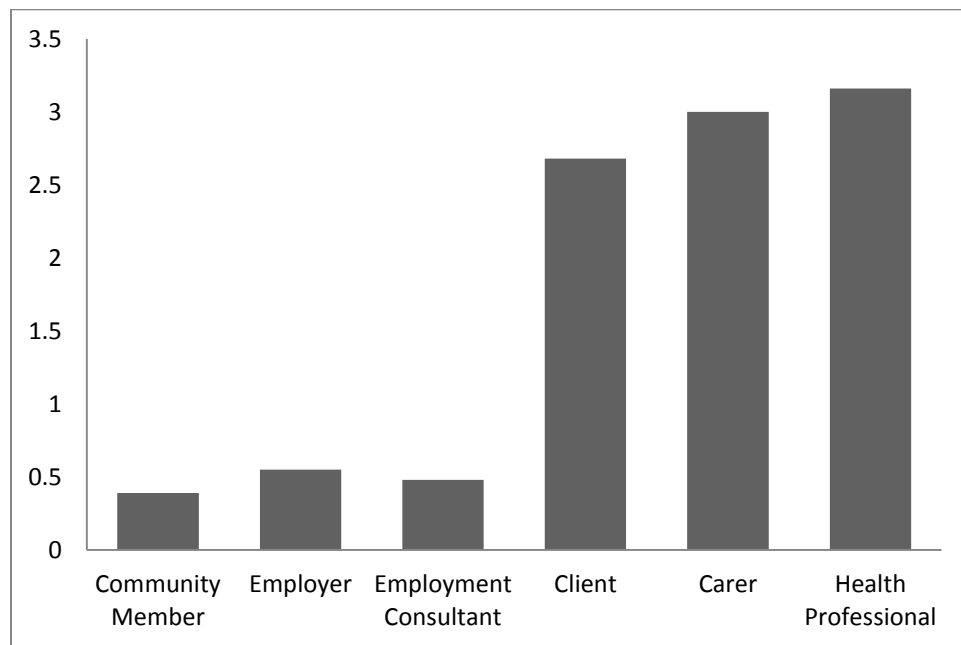


*Figure 20.* Tree map showing participant references to the impacts of medication side-effects on work. This tree map shows the number of references coded to each of the main medication side-effect nodes (categories).

The most problematic side-effects of medication in relation to work appeared to be tiredness, drowsiness and energy depletion. Respondents referred to physical impacts of medication such as weight gain with associated negative impacts on self-confidence. Effects of medication on cognitive functioning were also mentioned. Several respondents referred to the disruptive effects of a change in medication, including withdrawal effects and increased risk of exacerbation of symptoms with potential impacts on ability to work.

One client respondent described how a planned change of medication contributed to onset of another psychotic episode which culminated in the loss of his employment.

Figure 21 shows the average number of references to medication side-effects according to stakeholder group.



*Figure 21.* Average number of coding references to medication side-effects according to stakeholder group.

### **Personal attributes**

The personal attributes most referenced as potential barriers to work were motivation, self-management skills and self-concept issues. Other personal attributes seen to impact on employability include criminal history, physical limitations and other individual characteristics. The relative frequency of references to personal attributes for all stakeholder groups is shown in Figure 22.

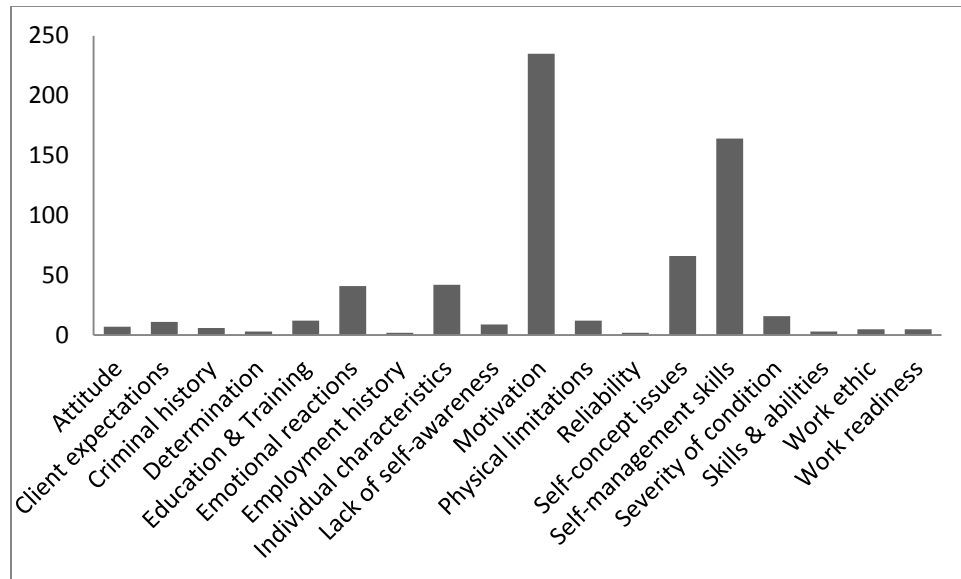
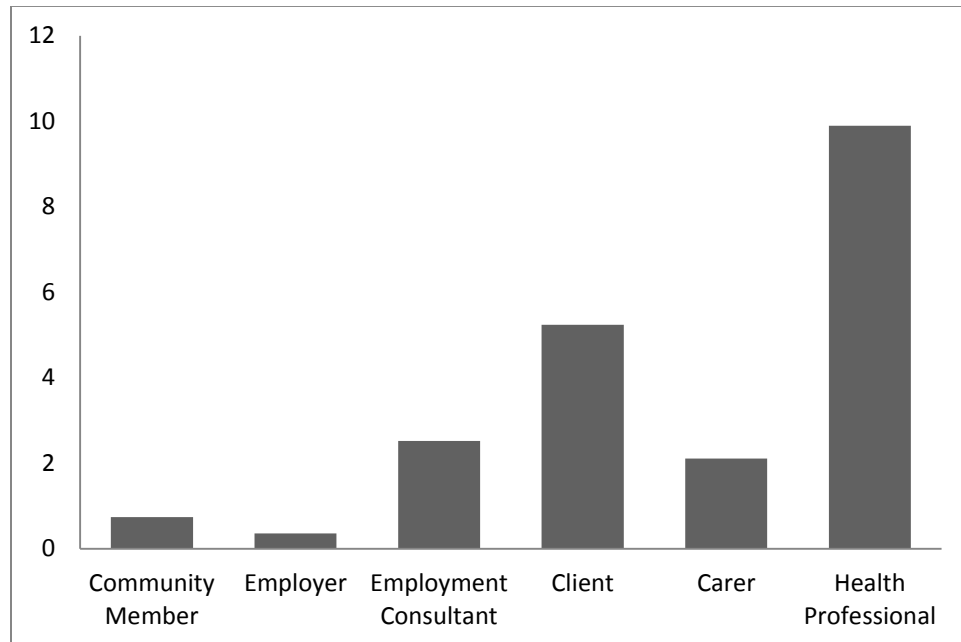


Figure 22. Participant references to personal attributes impacting work outcomes.

**Motivation.** Motivation was the personal attribute most commonly referred to by participants. Jobseekers with chronic and severe mental health conditions were seen to have impaired motivation to work:

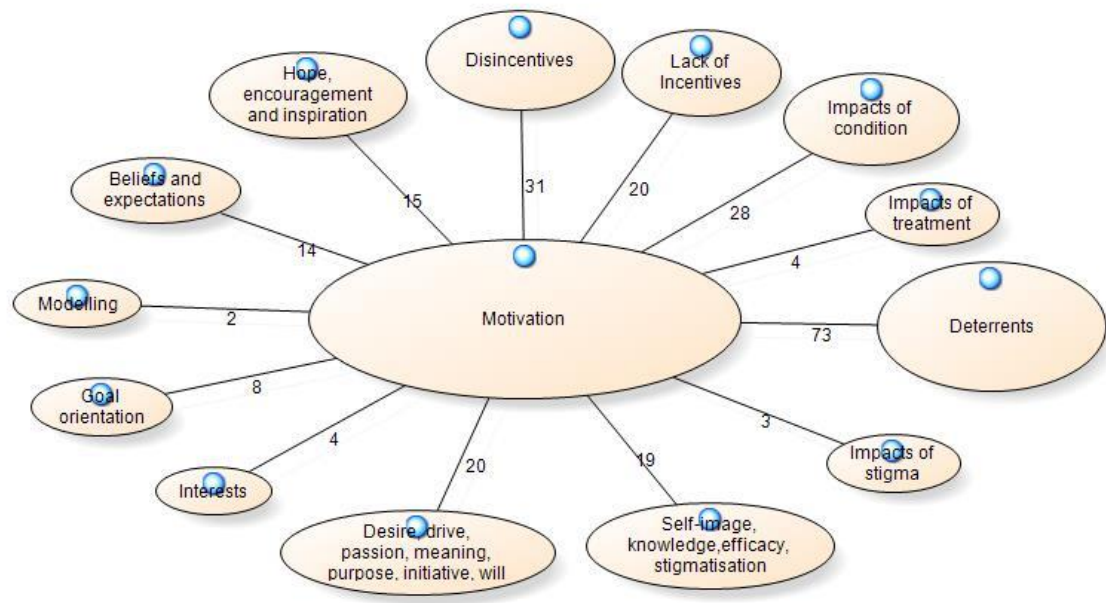
If it's a long-term mental illness, when it comes down to actually committing to work there is no ability to do so. There still seems to be very little motivation to take that next step. The reality of work, when it hits somebody in the face, just turns the majority of our significantly impaired mental health clients around and they walk out. (Employment consultant)

Figure 23 shows the average number of coding references to motivation according to stakeholder group.



*Figure 23.* Average number of references to motivation according to stakeholder group.

Participants identified multiple internal and external influences impacting on an individual's motivation to seek and maintain work. The most frequently referenced factors perceived to impact on motivation were deterrents, impacts of the condition and disincentives. It was clear from responses of participants that motivation is a dynamic factor which is influenced not only by personal qualities - such as drive, work ethic, determination and resilience - but is also powerfully influenced by external factors such as social attitudes, deterrents and disincentives. The most important factors affecting individual motivation are illustrated in Figure 24.



*Figure 24.* Factors influencing motivation to work in people living with psychosis. This model shows the node structure and coding density of references to factors influencing motivation to work in people living with psychosis. Numbers on connector lines represent the number of references coded to each node (category).

The main deterrents considered to impact on motivation were the type of work, impacts of the condition and impacts of past negative experiences. Participants considered suitability of job match, degree of job satisfaction and job status as important variables determining motivation.

...if you've had a really disrupted education and then the job opportunities left to you are lower than what your intelligence would allow you to do, you don't want to go and do it...I've never worked in a supermarket. I don't want to go and work, stand up in a supermarket...I'm not going to go from studying science at university to being a check-out chick. So there's a lot of people that are very intelligent people but their education was disrupted early... (Peer worker)

There was evidence that dislike of the type of work contributes to the struggle to get through the day. A client with bipolar disorder described her experience of persevering in spite of ambivalence about her career choice: “I feel so good when I come off duty. I feel I’ve done another day. I feel it’s an achievement. Nobody knows how hard it is for me to do that day”.

Deterrents to work included primary impacts of the condition itself such as demotivation caused by the illness itself, lack of drive, depressed or fluctuating mood, sleep deprivation, social withdrawal, auditory hallucinations and delusions, difficulties with cognitive functioning affecting ability to plan, sequence events and concentrate long enough in order to execute plans. Secondary impacts of the condition perceived to affect motivation included: sedative effects of medication; education and career disruption precluding employment appropriate to their ability and negatively impacting employment experiences; demoralisation; and fears. Fears included fear of the possible effect that employment or increasing work hours might have on their mental health; fear of relapse; and inability to sustain work due to a need to take time off work due to hospitalisation.

Past negative experiences were also seen to potentially impact motivation. It was suggested that past episodes in the workplace may have been so severe and traumatising that clients may fear a return to work due to concerns about being judged or a perceived lack of understanding in the workplace. Participants suggested sensitivity to past experiences of rejected job applications, stigma, discrimination or bullying may also affect motivation and self-confidence and lead to a fear of failure. Inability to recover their previous level of work functioning, or performing unstimulating or degrading work

were also seen to lead to demoralisation. Individual personal characteristics considered most relevant to motivation included personal drive, self-concept and expectations.

Lack of incentive and disincentives were also seen to affect motivation to work. The negative impacts of deterrents, lack of incentives and disincentives are discussed in more detail in Chapter 10, which focuses on systemic barriers.

**Self-management issues.** Respondents felt that some people living with psychotic conditions may desire to work but lack essential life skills and routines necessary to achieve sustainable employment. Several respondents emphasised the importance for people diagnosed with schizophrenia or bipolar disorder to take personal responsibility for managing their condition. The areas of self-management most referenced by participants were relationship with treatment, relationship with the mental health condition, capacity for self-regulation and repertoire of adaptive skills. The most frequently cited themes were adherence to medication, relationship with the condition and coping with emotions and stress (see Figure 25).

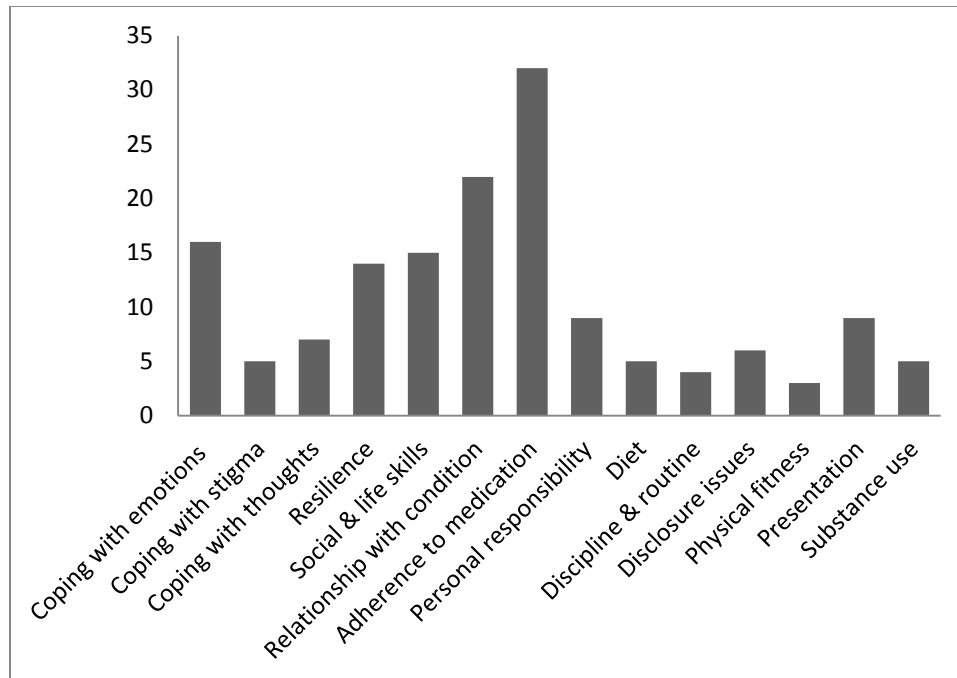


Figure 25. Chart showing participant references to self-management issues affecting work ability. This chart shows the number of references coded to each of the referenced self-management skills.

**Relationship with treatment.** Participants felt there was a limit to the support families and others can provide and that individuals need to take personal responsibility for seeking out and regularly attending psychiatric and psychological treatment. It was also felt there needs to be a willingness to access support from an employer, if needed, or to access available disability specific supports for study.

**Adherence to medication.** Non-compliance with medication was the most frequently cited barrier in terms of self-management issues. There was a common perception that people living with psychotic conditions do not comply with medication requirements. It was considered some people refuse to take medication out of personal choice due to a negative attitude towards medication or due to lack of insight (denial) particularly in the early stages of the condition. Some people were perceived to be



resistant to taking medication or may discontinue due to side-effects, the need to trial multiple medications and/or the long-term requirement for medication. Others, it was felt, may decide to stop taking medication because they feel it is ineffective, makes them feel worse, for example in the case of mania, or because they feel better and consider they no longer need it. Cognitive deficits in cases where the condition is not well controlled were also cited as a reason for non-adherence to medication. Another factor seen to affect medication adherence was the client's relationship with their treating health professional. It was felt that clients who do not have a good relationship with or do not believe in their treating professional were less likely to comply with medication requirements. Other factors seen to affect medication compliance included stigma, family support to take medication, cost of medication and accessibility of a chemist.

Participants referred to the impacts on functioning due to not taking medication regularly. Non-adherence to medication was seen to affect several areas: work attendance; work performance, including the ability to follow directions and complete tasks; and the ability to interact effectively with people in the workplace due to mood changes. It was also predicted that non-compliance with medication could result in workplace episodes, resulting in loss of employment and increasing difficulty in finding new employment. Non-compliance with medication was also perceived to be a precipitating factor in rapid destabilisation of the condition as well as threats and incidents of public violence.

***Relationship with condition.*** It was apparent that the relationship which people with schizophrenia or bipolar disorder have with their own condition varies, and may constitute a barrier to employment. Some were perceived to be non-accepting of their

condition, to “fight” it, be in denial and blame others. For some it was seen to be “in the forefront of their mind, their lives, and it’s like their whole identity is schizophrenia or bipolar”. There were others who reportedly feel like they are a victim of their mental health or may even use the condition as an excuse to evade work or manipulate others. Others, however, were perceived to have developed a comfortable relationship with their condition in which they “own it”, live with it, understand it and speak about it. An employment consultant stated she found such people much easier to assist. Some people with lived experience of psychosis appear to be so busy living their life they forget that they have it:

....like, honestly, I forget about it, all the time, that I even had a mental illness... even though I’ve had in the past very serious...four or five major episodes and admissions. It’s like it goes completely away and you’re so busy living your life that you forget that you even have a mental illness. (Peer support worker)

A participant with bipolar disorder, in describing her acceptance of the condition commented: “....you’re just gifted in a little different way.” Another participant who had lived with schizophrenia for many years even seemed to have a joking relationship with his condition:

I’ve got a common joke that I used with very close allies, close friends, and I say, “I’m a psycho and I’m proud of it”, you know. I don’t mean it to be ill on my behalf or ill towards any of the other clients...just something I say because I have worked hard to maintain my life...

***Self-regulation.*** Self-regulation was seen by several participants to be an important aspect of self-management. Self-regulation refers to the ability to regulate

involvement in situations or activities likely to exacerbate the condition, pacing of work-related activities and life-style regulation. One respondent with schizophrenia expressed a need to regulate the amount of stress he put himself under, due to a perceived relationship between stress and onset of symptoms. A client with bipolar disorder reportedly self-excluded from gambling situations while another client said he purposely avoided certain types of study subject matter due to a perceived risk of exacerbating his condition. There was also a perceived need to be careful of the *type* of jobs undertaken, including a need to avoid long hours, ensure sufficient time to “re-charge” and feel comfortable and safe in the work environment.

...you have to be careful what sort of jobs you take on. Like you've got to make sure...if it's really long hours or you feel it's going to impede your ability to re-charge...I mean that's probably the same with everybody but that's what I look at ...and also I just need to feel comfortable and safe I guess you'd call it for me to be at maximum. (Client with bipolar disorder)

Lack of pacing of work-related activities and, in particular, overworking were seen as potential barriers. An employment consultant pointed out that some clients may be highly motivated, taking on more hours than they are able to sustain, and suggested that clients need to build capacity to ensure sustainability of employment. Another commented that some employees may put too much into the job initially and find they become exhausted and cannot sustain it. Making decisions about how much work to take on and being able to decline the offer of extra work when financial issues are pressing were also seen to be issues requiring self-regulation. Other potential issues requiring self-regulation include

presentation, decisions about disclosure and life style regulation such as diet, sleep, substance abuse and discipline/routine.

***Adaptive skills.*** Respondents suggested some people may lack necessary adaptive skills, which would make it difficult for them to cope with work situation demands. These include the ability to manage emotions and stress, cope with stigma, display resilience and apply social/life skills. Concentration difficulties as well as the ability to manage negative cognitions were seen as factors impacting work ability. Some respondents mentioned coping strategies they had used such as awareness of the need to “concentrate very hard” on tasks requiring full attention and deliberately “put on an act” in difficult working conditions. While some respondents appear to have developed functional coping strategies in these areas, others were seen to lack essential skills needed to work.

Inability to effectively manage stress was seen as an important barrier to employment. This includes fear of the unknown or inability to manage stress in relation to public transport. Respondents pointed out lack of insight or stigma may prevent disclosure and early help-seeking on an employee’s part when stressors start to build. Resilience and the ability to cope with stigma were seen to be an important factor in gaining and sustaining work. Social and life skills including time management skills and interpersonal skills were also seen to influence work capacity.

***Self-concept issues.*** Self-concept issues were identified as important personal attributes having a significant impact on employment. Self-concept issues included issues such as self-esteem, self-confidence, self-belief, self-identity and self-stigmatisation. The most commonly referenced self-concept issue was lack of self-confidence. Participants

reported many people living with psychotic experiences suffer from a loss of self-confidence due to the impacts of the condition itself, loss of sense of personal control during the treatment process, side-effects of medication, and the effects of stigma. Lack of self-confidence was seen as a barrier to undertaking and persisting with job-seeking activities as well as meeting requirements to sustain employment. It was felt people may lack confidence in their own ability to work, confidence in an employer's willingness to employ them, confidence to access supports, cope with rejection, fit into the workplace or have difficult conversations with their employer. A carer commented: "...there's the aspect of the lack of confidence and you've got to get through that sort of area, where it really is a severe lack of confidence and the stress that comes with lack of confidence."

A community member observed, "...when I was working in the employment agencies [with] those who did have problems, I found their biggest problem was believing in themselves." There were, however, clearly individual differences in the degree to which people living with psychosis were affected by self-concept issues. A participant with bipolar disorder stated, "I don't see myself as different from anyone else out there". Respondents with lived experience also seemed to differ in the extent to which they had internalised social stigma, with some making statements indicative of self-stigmatisation.

**Severity of conditions and degree of disability.** There was acknowledgement there is a wide spectrum of severity and frequency of recurrence of these conditions, and that many people may only be mildly affected. Several participants considered that individuals in the acute phase of an episode or with a more severe presentation would experience the most barriers to employment. People with these conditions were also seen

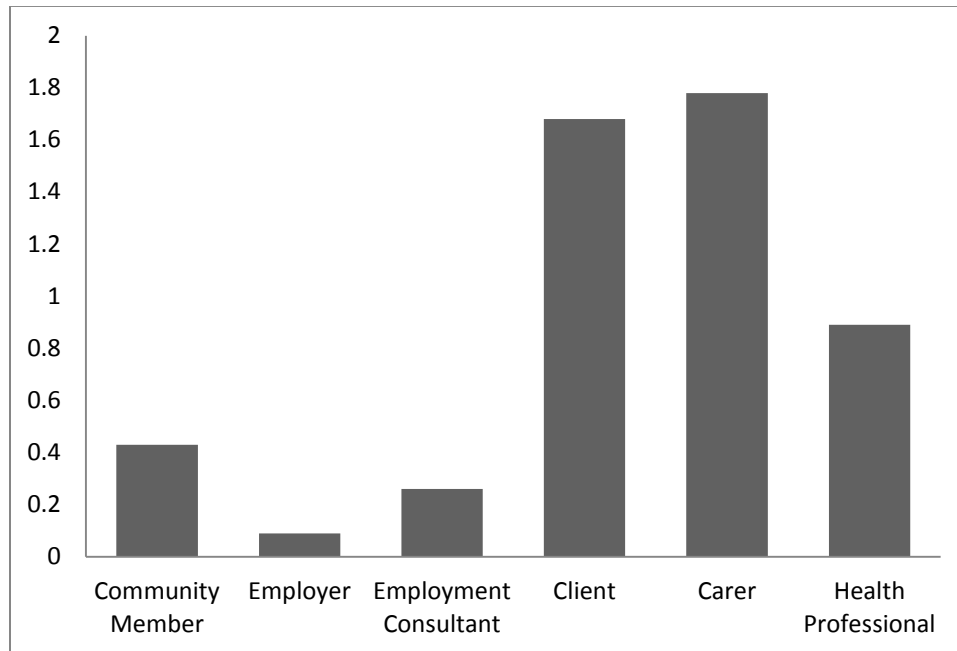
to be on a spectrum in terms of degree of incapacity, ranging from those unable to function in the workplace to highly functional individuals. It was pointed out diagnostic labels as well as employers do not usually recognise this range of variability:

But when you go down and fill in the form and it says have you had any of these mental illnesses: bipolar, schizophrenia blah, blah, blah, blah, and you got to tick a box you can't say, "Oh I'm only sort of one sixteenth bipolar. I'm actually really quite normal". You just got to tick that box. (Community member)

**Physical limitations.** Respondents mentioned various physical limitations that would impact on their ability to work. Some participants referred to old physical injuries that would impact on their work capacity. Lack of physical fitness was identified as another barrier. It appears that impacts of drugs, sedentary life-style and work de-conditioning may all play a role in lack of physical conditioning.

**Criminal history.** Participants referred to the impact of a criminal history on ability to find work: one client participant with a criminal driving history said he was unwilling to even apply for jobs due to concerns about police checks; another, despite being well qualified, considered his application for a volunteer position had not been followed up due to a criminal history. A criminal history was also seen to raise concerns and restrict work options according to the nature of the offence.

**Individual characteristics.** Participants, particularly carers and clients, pointed out there are individual differences among people living with the same condition which affect their ability to gain and sustain employment (see Figure 26).



*Figure 26.* Average number of coding references to individual characteristics according to stakeholder group.

A client with bipolar explained “we’re not all in the same pot.... we’re not all tarred with the same brush it’s all different”. They pointed out these differences were not wholly attributable to the condition itself but other factors also play a role. Individual differences considered relevant to work outcomes included personality and character traits. An employer who reported success employing a number of people with schizophrenia pointed out that people with schizophrenia have good and bad qualities, just as do “normals”. Participants considered that a wide range of individual attributes could potentially influence employment outcomes. Respondents without educational qualifications seemed to experience more difficulty with job-seeking than those with qualifications.

The people that I see around me in the hospital system who don’t work...it’s usually to do with...other things than *just* the mental illness. It’s to do with their

personal situations, personal attributes that's what I see around me... (Peer support worker).

### **Personal circumstances**

Respondents identified a number of personal circumstances likely to affect employability. The most frequently referenced barriers were lack of family and social support, transport issues, financial insecurity and living environment. A psychologist questioned whether it was the mental health condition itself or associated personal circumstances which best accounted for the low employment rate: "Is it the mental illness that's keeping them out of employment...or is it not- is it all the other risk factors?"

**Family and social support.** The most frequently referenced personal circumstance affecting employment outcomes was family and social support. A peer consultant stated: "...a big thing in my success was that I always had those supports...but if people don't it's very difficult". Participants suggested that social connectedness in neighbourhoods and the extended family has broken down in the last fifty years and that people have less of a sense of accountability for the wellbeing of others. Lack of supportive family and social networks were seen as potential barriers to work:

...he's living this life on the street so I think that people can easily fall into this through lack of supports and I think sometimes that people become unwell so many times that they isolate, they lose contact with their family, they lose contact with their friends, they move around so that they don't have those supports... (Peer support worker)



Family dysfunction, family stressors, family attitudes and expectations were also identified as potential barriers to employment. An employer described her experience of parents who have been “at wit’s end”.

...it’s such a hard illness for family members to live with. As soon as they lose the family support or they become homeless the condition seems to get worse because everything spirals out of control. (Employment consultant)

Lower socio-economic background, lower educational level and lack of a nurturing and supportive environment were seen to be factors that could adversely affect compliance with treatment. It was pointed out recurrent episodes can lead to increasing isolation, loss of contact with support networks and homelessness and that loneliness can be debilitating and precipitate depression.

**Transport.** Participants reported that many people living with psychosis may experience anxiety about driving or using public transport, may be unable to afford the costs associated with owning a car, and are reliant on public transport:

...it’s more time-consuming to get to places so that brings in the issue of getting up early to get somewhere. If you’re coming from one end of the Coast, you’ve got to catch a couple of buses. You can be getting up at five in the morning...which is hard if you’re on really heavy anti-psychotics... (Peer support worker)

**Financial insecurity.** Financial vulnerability was seen to constitute a barrier to work and engender fear of loss of social security payments. Financial barriers cited included work-related travel costs, which may be greater for those living in more affordable outlying areas; costs associated with car registration and repairs; travel costs to

attend courses; cost of internet access to do online courses; medication and other health related expenses, and cost of union membership.

**Accommodation.** Lack of stable accommodation was seen to constitute a major barrier to employment:

...stable accommodation is huge. Sometimes we find we're fighting battles to stabilise that prior to even considering how we're going to look for work for somebody. Everything that's around a person has to be really stable for us to be able to do what we need to do for them and then it has to remain stable to keep them in work. (Employment consultant)

Circumstances in public accommodation as well as dispositional factors may make it difficult to adapt to shared accommodation options. Carers described their perceptions of conditions in public housing in this way:

P88: You know what they do in Sydney? They put them in housing commission homes. I know of instances of it. They terrorise the whole building.

P87: Well they would

P84: They terrorise themselves

P88: They're put there and there's no support. They just put them there.

P85: And they feel they have to put up with it what's more. If you put [son's name] in a place like that they think ah well I've just got to put up with drug addicts and people screaming and yelling at each other and pulling a knife on me and...

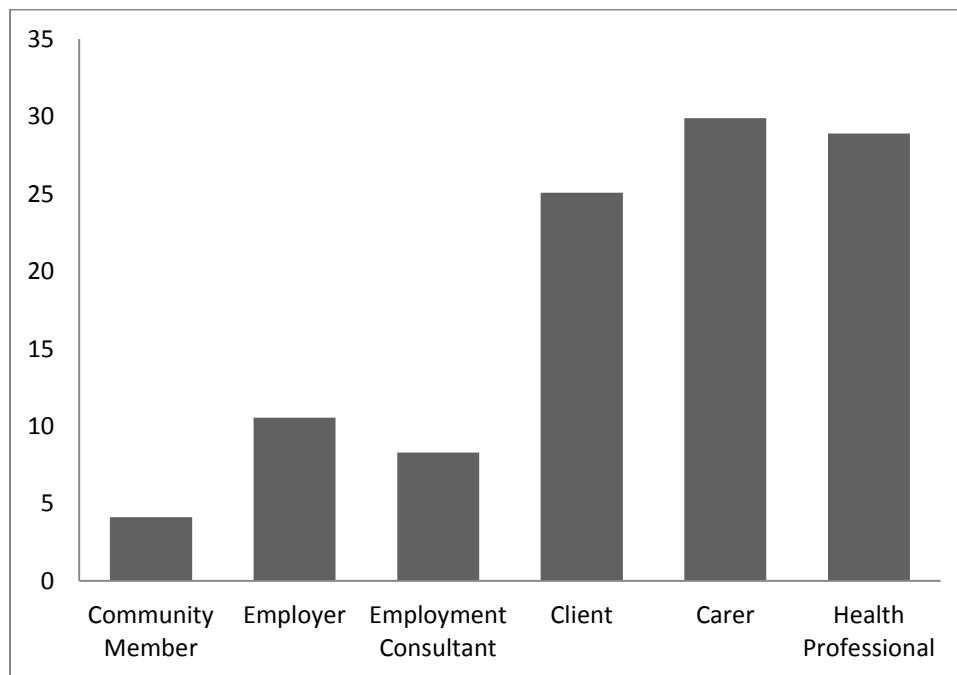
P84: And some of those drug addicts are suffering from mental health [conditions] too and don't get support...

P85: That's exactly right (Carers)

### Summary of Individual Barriers

The most frequently referenced individual factors were personal attributes (641 references), impacts of the condition (627 references) and personal circumstances (123 references). The most frequently referenced personal attributes were motivation (235 references) and self-management skills (160 references). These findings suggest that while impacts of the condition itself constitute significant barriers to employment, individual personal attributes and personal circumstances play a more important role in employability than is generally recognised in the literature.

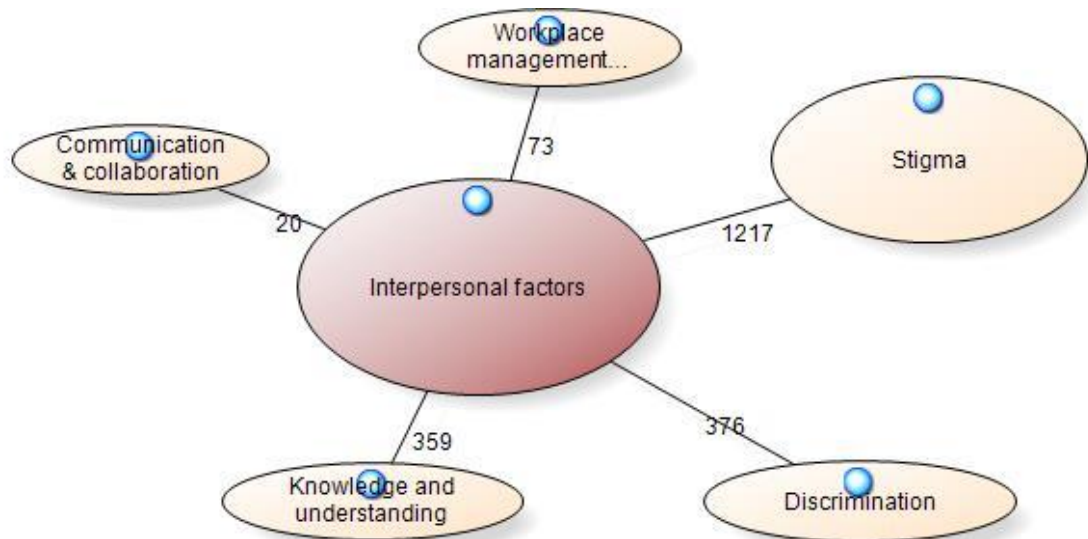
The average number of coding references to individual factors according to stakeholder group is shown in Figure 27 below.



*Figure 27.* Average number of coding references to individual factors according to stakeholder group.

### Chapter 9: Interpersonal Factors

Interpersonal barriers were defined as factors inherent in interpersonal interactions. These include attitudes, perceptions, beliefs, expectations, emotional reactions, and behaviours pertaining to the employment of people living with psychosis. This section includes references to knowledge and understanding, stigma and discrimination, workplace management issues and communication and collaboration. As can be seen in Figure 28 below, stigma was the most frequently referenced interpersonal barrier.



*Figure 28.* Summary of model of interpersonal barriers to employment. The numbers entered adjacent to connector lines represent the number of participant references, or coding density, for each of the main barrier nodes.

A more detailed analysis of interpersonal factors as barriers to employment is provided in Figure 28. This chapter will focus on description of the contents of the most heavily populated nodes.

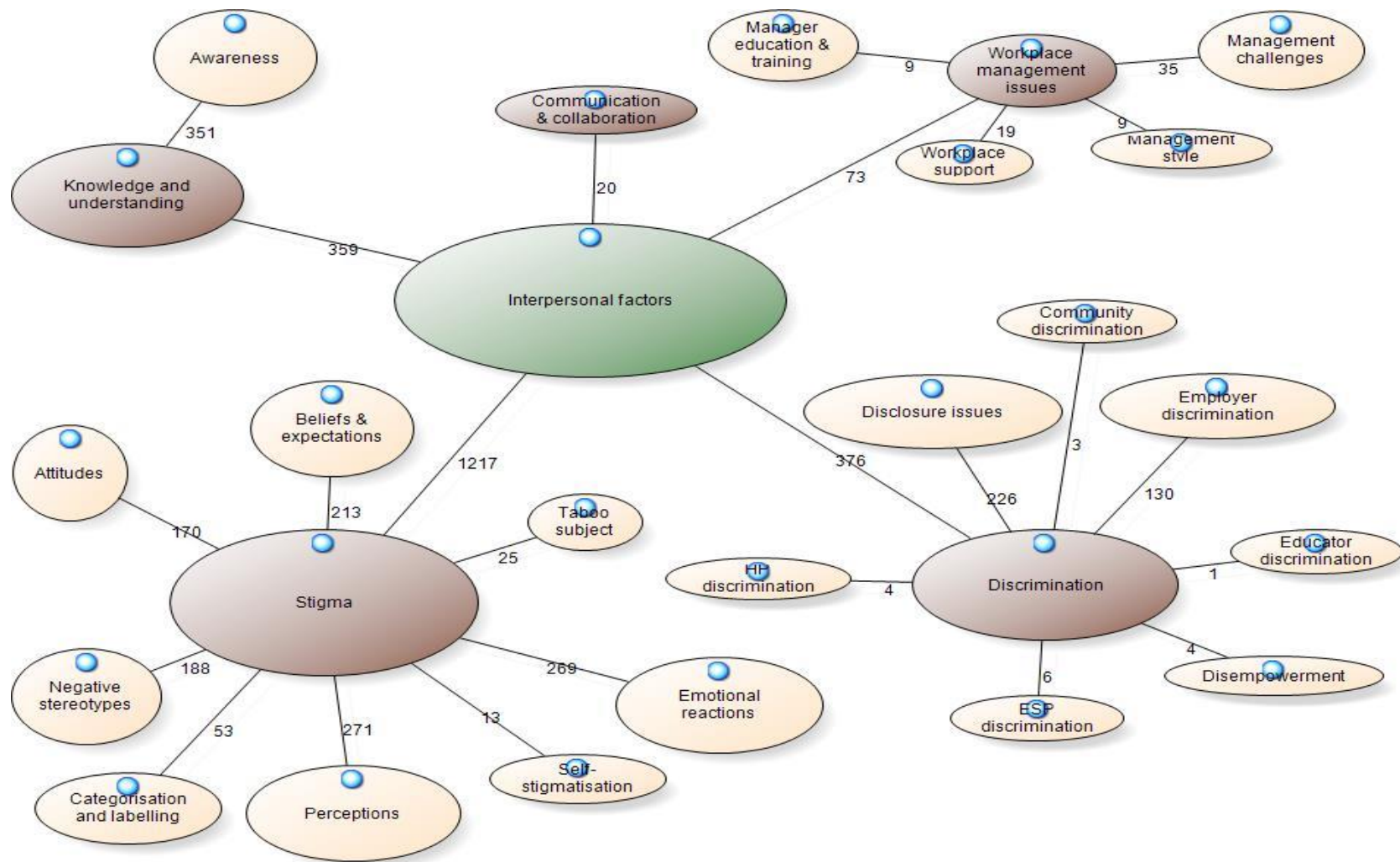


Figure 29. Second order analysis of interpersonal factors as barriers to employment.

**Lack of Knowledge, Awareness and Understanding**

The most frequently referenced knowledge gaps were in relation to community knowledge and understanding, employer knowledge and understanding, and accessibility of information. As expected, most participants had some knowledge of either schizophrenia or bipolar disorder, which aligned more or less with current knowledge of these disorders as objectified in the Diagnostic and Statistical Manual of Mental Disorders IV-Text Revision (American Psychiatric Association, 2000).

Community members who claimed to have some knowledge and awareness of schizophrenia or bipolar disorder tended to be those who had family or friends affected by the condition. Several community respondents, including respondents across a range of professional occupations, openly acknowledged their lack of knowledge about bipolar disorder and schizophrenia. One community participant stated, “I don’t know very much about mental illness” while another said, “I can’t talk about schizophrenia because I don’t know enough about it...”

**Lack of exposure.** Respondents frequently referred to the low visibility of mental health conditions in the community. Participants identified the following reasons for this low visibility:

- Schizophrenia and bipolar disorder are less easily identifiable conditions than physical disabilities.
- Social withdrawal and isolation, commonly associated with these conditions, may limit opportunities for social interaction with the public.
- Treatment outside of community settings or in specialised services renders people with psychotic disorders “out of sight and out of mind” to the average citizen.

- Non-disclosure or “partial” disclosure of a condition by clients was seen as an important barrier to exposure. A client respondent described the situation as follows:

I guess because, well, it wouldn't be out in the open. I don't think people would sort of want it advertised that they've got schizophrenia or advertised that they had bipolar so you could employ them but the only person who would know would be themselves and maybe a boss or a manager or something. (Client with bipolar disorder)

One community participant commented, “I haven't seen a bipolar”, while others were uncertain whether they had ever interacted with, employed or worked alongside a person with schizophrenia or bipolar disorder. It was pointed out that, in organisational contexts, non-disclosure as well as confidentiality requirements could prevent this information from being brought to the awareness of co-workers.

Non-client respondents with previous exposure to these conditions had usually gained this experience through contact with relatives or acquaintances with the condition or exposure in paid or volunteer work settings. A respondent who had grown up in a mental institution and another who had worked in a non-clinical role in a mental institution considered themselves “very fortunate” and “lucky” to have had this experience.

A number of participants referred to the negative implications of non-exposure to psychotic conditions. A peer support worker said, “I think what people don't see...it's unusual...and then they're scared of it, and the more [exposure] there is of it, they probably would get less [scared]...as long as the people are well of course”. Lack of

exposure was seen to perpetuate lack of understanding, misconceptions and inability to identify and respond appropriately to early signs of the condition. A parent retrospectively reflected: “How could we be so silly? How could we not have seen that? But we had never been exposed to it so we didn’t know.”

It was felt that non-exposure of community members to people living with psychosis also affects their perceptions and social competence in interacting with people with these conditions:

...it’s like you meet someone in a wheelchair with spasticity or something.

You’re not sure whether to stop and talk or whether to pretend you haven’t seen them, because you’ve not dealt with it. I think mental health falls into that. If you haven’t dealt with it you have different perceptions to someone who has. (Family member)

A community member observed that many people prefer to maintain social distance due to fear and perceived lack of skills to interact with a person with psychosis: “...a lot of people don’t have the skills. They would be scared because they’d think they had to *do* something.”

Participants pointed out that clinicians working in mental health services tend to be *selectively* exposed to people who are severely affected by psychotic conditions, and may not gain the same degree of exposure to people who recover and go on to lead normal lives in the community. It was felt that this can negatively influence their perceptions, beliefs and expectations of recovery.

**Community knowledge gaps.** Participants who were community members asked a wide range of questions during focus groups in an effort to clarify their understanding



of conditions. The following gaps in knowledge, awareness and understanding were identified: lack of knowledge of psychiatric nomenclature; misconceptions about the nature of psychotic conditions including what triggers it; how it affects people; efficacy of treatment; how to interact with a person with schizophrenia or bipolar disorder; stressors to avoid; support needs; and how to manage a crisis.

There was a paucity of understanding of psychiatric terminology. A community member stated: “Ah, there’s always risks especially with people with dyspolar (sic), dibopar (sic) or whatever you call it.” Participants asked numerous questions in an attempt to clarify the nature of conditions. A clergyman enquired, “Could you say what the difference between bipolar and schizophrenic is...or *is* there a difference?” A community member stated, “... I haven’t seen a bipolar....that would be far less identifiable wouldn’t it than say...[a physical condition]?” The same participant asked, “Are there degrees of bipolar and schizophrenia?” Another community member enquired, “How many people have bipolar, how many people have schizophrenia and how many people lead normal lives compared to these incidents that you read about that don’t take their medication?” A parent said wistfully, “Had I known what the symptoms of bipolar were, for instance, or how to recognise it, we might have done something a lot earlier than ever happened. We had no idea...”

There also seemed to be uncertainty, misconceptions and illusions among some community participants about the capacity of medical science to effectively treat these conditions. A student teacher said, “I don’t know whether it’s the same with schizophrenia [as bipolar disorder]...like medication can keep it under control.”

A community member and former employment consultant asked, “Do you know much about schizophrenia...enough to know if they can overcome it”?

Participants referred to a lack of confidence in interacting with people diagnosed with schizophrenia or bipolar disorder. A community member asserted, “...people are unsure how to deal with someone with a mental illness...I don’t know what people with schizophrenia need.” Another commented, “I don’t know if a schizophrenic or a bipolar person would have a carer.”

Questions asked by community members revealed community knowledge gaps concerning work-related issues. One participant asked, “Is it illegal to fire someone if you find out that they have it?” Other work-related queries were: “Do people have to disclose that they have schizophrenia...when they apply for a job?” and “Is there insurance [for employers] for that?” There were also questions about work capacity: “In bipolar disorder, don’t depressive episodes...last for a really long time so that might upset, you know, actually going to work?” An experienced employment consultant observed:

...people with schizophrenia...there’s times when they’re stable and there’s times when they’re unstable. When they are stable they are capable of working and being very fulfilling contributors to society...most of the people in the wider community only understand schizophrenia from a negative perspective and they don’t understand that there’s highs and lows and lows and highs and in-between things. (Employment consultant)

Some participants made assertions and then immediately expressed doubts about the validity of their own statements. A community member stated: “...the person wouldn’t be a danger to him or herself perhaps - I don’t know whether that’s true- or the

other employees”. Another community member said: “...I mean people know that people off their meds can be aggressive....that may not be right but (laughs)...” Yet another responded “... someone with perhaps limited work, not skills, because I think a lot of them are very intelligent, aren’t they?”

Some respondents made statements that indicated misconceptions, misunderstandings and confusion. A community member stated, “Well, if you know you’re mentally ill, you’re not mentally ill.” There was evidence of stereotypical ideas and misconceptions of mental disorders, particularly schizophrenia, which was referred to as a “split personality” or Jeckle & Hyde:

I don’t know anything about schizophrenia really other than what we hear on the telly.....I’ve lost the word now...schizophrenic...but that sounds as if it can be a pretty terrifying thing with the sudden mood swings and sort of Jeckle and Hyde thing. They must be probably intelligent and there must be things that they can do, perhaps in a solitary way. I don’t know. (Community member)

One participant proposed, “Certainly issues like schizophrenia and bipolar, you know, I mean might be seasonal or might have particular times or mechanisms, which’ll make it more likely to be an issue in a workplace.”

Respondents with schizophrenia protested strongly against the tendency to be treated as if they were intellectually impaired. There was ample evidence that people confuse mental disorders with intellectual impairment:

I keep getting confusion between mental illness and sub-normality. You know, you see a lot of people that might have Down’s Syndrome. That’s an obvious one...you can pick it...and then the sub-normal person that does funny things,

and you don't know whether they're mentally ill or actually sub-normal, you know, born with a mental deficiency. I don't know. What's the difference?

(Community member)

Insights provided by participants in this study suggested some other community misconceptions, including exaggerated concerns about the potential for aggressive behaviour:

He's not aggressive because he's aggressive. He's *frightened*...and the public perception probably is pure aggression...they're all nuts, they all go crazy, they steal from their family and they take knives out and they attack the police cause that's all we see in the press. (Lawyer)

...most of the people in the wider community only understand schizophrenia from a negative perspective and they don't understand that there's highs and lows and lows and highs and in-between things and therefore there is a very strong fear factor, scare factor and how do I talk to these people, how do I approach these people, how do I even communicate with them... (Employment consultant)

Participants also asked many rhetorical questions. A community member asked:

"How do you train me to accept that person to be capable of caring for an infant that won't stop crying? How?". Another said, "I think there is a need for education but how...? Would it start with the parents or the children, you know?". A participant living with schizophrenia asked "...how do you change the common idea that people with mental illness are retarded in the private work sector, you know, to change that for them to get jobs. How would you do that?"

In discussing how they had acquired their knowledge of these conditions, only two participants disclosed having received any form of educational experience at school. Participants referred to a tendency on the part of those inexperienced in dealing with people with these disorders to obtain their information from the media, particularly the news, and general conversation. Many respondents referred to television and movies as their main source of information regarding these conditions. There was evidence that the level of mental health literacy among young people was also not good and that unless they had friends or family with the condition young people tended to avoid or not take seriously educational opportunities arranged at school. Respondents felt that young people may lack maturity to interact sensitively with people with a psychotic condition and were seen to display the same range of emotional responses as adults when faced with unusual or confronting behaviour. One participant felt that most funding and awareness training focuses on anxiety and depression and that other mental health conditions receive insufficient attention.

Not only was there evidence of community ignorance, but responses indicated that, unless a person has a friend or family member affected by one of these conditions, there may also be a reluctance to learn about it due to the taboo nature of these conditions.

**Employer awareness and understanding.** There was a perceived lack of education of employers in the private sector. Respondents, including employers themselves, felt that employers are not well enough informed, and lacked understanding of schizophrenia and bipolar disorder. A businessman commented "...I can't talk about schizophrenia because I don't know enough about it..." while an employer said, "...I

know nothing about it. As I say, I did employ this person.” A businessman referring to management remarked, “They don’t know anything much about it”. This participant, who had worked in an administrative role in a mental institution, talked about the impacts of non-exposure on employers:

...most of the HR people wouldn’t have a clue...and I mean that goes for most of the population (laughs) ’cause unless you’ve been there and experienced and done a little bit of work on it. I mean...it’s opened up my mind much more than it used to be and, you know, if you had a sort of an inverted commas ‘normal’ upbringing, all those sort of things you’re not exposed to in any way...

(Businessman)

Lack of understanding was seen to give rise to automatic assumptions, misconceptions and imagination. An employer remarked, “... there could be a misconception about what it’s all about and I must admit I largely live in that category”. There was a perception that employers may also be unwilling to learn and understand unless they have a family member affected by a mental health condition. Social taboos around mental conditions also appear to prevent sharing of positive employment experiences among employers.

Participants surmised many employers may, unwittingly, employ a person with a serious mental health condition. The fact that conditions are not always visible means employers may unknowingly employ a person with psychosis who may or may not subsequently disclose their condition. This left some employers uncertain how to react when a condition is later revealed during the course of employment. There was a measure of empathy expressed towards employers. One client with bipolar disorder questioned the fairness of expecting employers to be trained as they already have a tough enough job

running a business: “So is that fair to them? They have to run a business so that’s tough enough...” Another, however, suggested that employers may ‘worry’ about their own lack of information and the ‘unknown risk’. There were also concerns that employers would lack the necessary knowledge and skills to provide effective management and exercise duty of care in the workplace. Employer knowledge gaps and misconceptions were identified in relation to the characteristics of psychotic conditions; workplace adjustment needs; legal rights and responsibilities and business risks. Perceived employer knowledge gaps included knowledge about the nature and degrees of severity of bipolar and schizophrenia. An employer enquired, “So presumably there are degrees of this [bipolar disorder]?” Others were interested in factors in the work environment likely to exacerbate these conditions:

P47: I think it’s probably from a relative ignorance of the characteristics of some of these conditions but...do some of these conditions lend themselves to emergence when they’re under pressure? Like if they’re in a pressure job, is being under pressure for any sustained period going to, you know...?

P43: I don’t know...does it? (Employers)

Employer misconceptions and uncertainty were evident in the responses of some employers. For example, a project manager commented, “With the schizophrenics, because they have this swing between personalities, it’s a bit more difficult to employ them because you’re really not quite sure who you’re employing, I would imagine.” Participants pointed out that due to employers’ lack of knowledge and understanding, workplace behaviour may be misinterpreted and inadequate recognition given to prior skills, ability and training.

Respondents also referred to a lack of employer understanding of functional impacts. A client with bipolar disorder explained, “I’ve told my last two employers and... they’re a bit understanding but they don’t fully understand how big an impact it can make.” Lack of employer awareness and understanding was attributed to a lack of education and training opportunities for employers. It was also attributed in part to the invisible nature of the condition. A number of respondents indicated that the less visible nature of these conditions would render it more difficult for an employer to understand the nature of their limitations and workplace adjustment needs. A community member commented, “It’s probably a lot more easy to employ somebody with an obvious disability isn’t it like a wheelchair or something like this because you know their limitations.” Similarly, an employment consultant observed, “If someone has one leg shorter than the other, employers can see a visible disability but if someone has things going strangely in their heads it’s not visible to society.” Another participant expressed a similar view:

So mental illness, and schizophrenia being part of that...is not an illness that can be seen, it’s not like a broken arm... you could have ten people working at that particular employer and five of them might have mental illness but you couldn’t tell that from a distance... It can’t be seen so easily... (Employment consultant)

The prodromal symptoms of psychosis may also be less obvious to an employer:

....it’s not like they’re going away for a week and they have a cold and the employer can see he’s got a...he’s not going to come in this week...he sounds really crook. The employer and people would very rarely see someone who’s



psychotic because if they become that bad they're usually in the hospital.

(Employment consultant)

Employers appeared to lack knowledge of their legal rights and responsibilities in relation to recruitment and employment of people with schizophrenia or bipolar disorder. Issues raised included an employer's right to elicit information about a prospective employee's mental health history including the severity of a mental health condition; an employer's right to disclose an employee's mental health status to co-workers; and legal concerns pertaining to dismissal. In the absence of clarity on these matters, employers seem to have developed and implemented their own approaches to these issues.

Employers were perceived to face the fear of unknown business risks and lack awareness of factors that might help to control or manage potential risks to the business.

I think people don't know enough about it. Like I don't really know what someone with schizophrenia actually acts like or does on a day to day basis that's so different. So they just don't know. So it's a risk that you don't know.

(Business graduate).

It was also observed that even if employers *do* have a general understanding of these conditions, they may still be uncertain of the implications for their role as an employer and may lack confidence in their capacity to provide appropriate workplace support. A business manager opined: "I think if employers were aware of those things they might be less likely to employ cause they're unsure of what those conditions are and what they might mean for their role as employers." An employer, reflecting on personal experiences employing people with psychosis, said: "...we knew nothing about it so we were hesitant

initially that they couldn't complete the tasks that were asked of them etcetera. We've totally changed our view so I think really people don't know enough about it."

**Employment service provider knowledge gaps.** One employment consultant commented there are some employment consultants who believe that people with schizophrenia can't work: "I've heard people that have just started say but this person can't work they've got schizophrenia. So, you know, if you've even got that in an employment consultant then how do you sell that to an employer?" Disability employment providers and co-workers were described as being on a new learning "curve" due to their unfamiliarity with the needs of people with psychotic conditions. Respondents referred to a lack of knowledge and understanding of mental health conditions on the part of disability employment providers (See also page 220).

**Awareness of services.** Participants identified lack of an appropriate level of awareness regarding government employment programs across all stakeholder groups, including the range of services offered, type of staff employed and location of services. It was evident that health professionals in both public and private sector may be unaware of employment assistance programs and therefore unable to discuss them with their patients. Health professionals commented on lack of accessible information while one commented that such information "competes for space". Carers reported lack of information or difficulty accessing information regarding employment services. Client participants also reported gaps in awareness of employment programs. One client respondent described how, during a period of exacerbation of his condition, he had actively sought support to maintain his employment but had not been informed about the job in jeopardy program

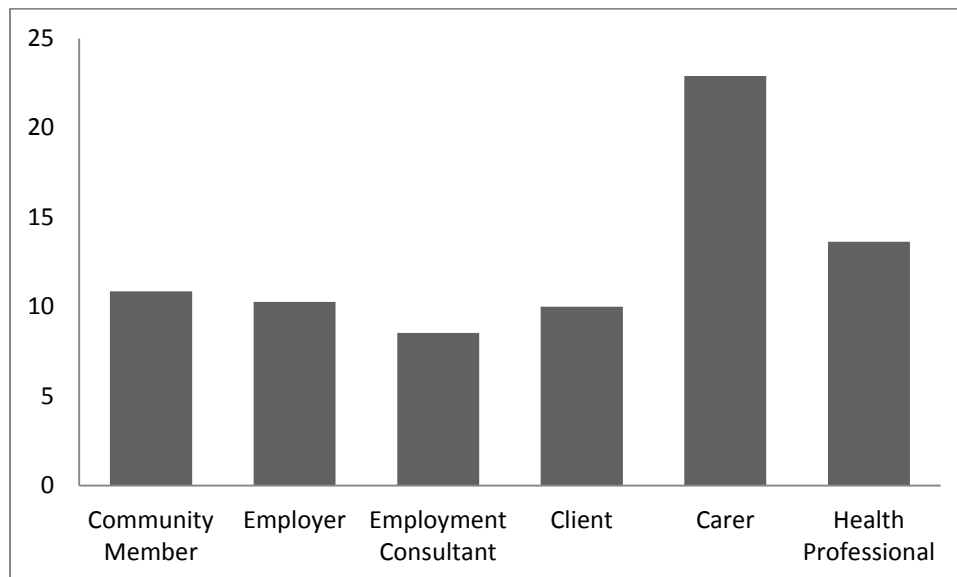
(see quote page 235). There was also a perception that people on a disability support pension are unaware of services to support them to return to work.

Health professionals and community participants also acknowledged lack of awareness and understanding of social security regulations, including provisions and implications for disability pensioners returning to work. Health professionals and community workers indicated that more knowledge and information would assist them to support people and allay fears around return to work.

Respondents also pointed to lack of publicity and difficulty accessing information on mental health services and support. It also appears that some general practitioners may not be aware of government funded mental health care plans.

### Stigma

There was consensus among participants that stigma associated with serious mental health conditions is a major barrier to employment (see Figure 30).



*Figure 30.* Average number of participant references to stigma according to stakeholder group.

A client remarked, “I think what’s happened in Australian society is that people with mental health problems are now lowly animals. I think they’re treated like animals in Australia...not like humans”.

Another theme was that of unwanted waste. One client referred to people with a serious mental health condition being “put on the scrapheaps for the rest of their lives”.

A carer in describing the resourcing and services for mental illness said: “They look at mental health like the dirt of all illnesses”. One employment service provider saw her service as a “dumping ground” for people who had not been adequately assisted by a prevocational support stream service. One client felt employers regard disability people as “scrap from the bottom of the barrel” if they’re looking for workers for their business.

Social stigma was identified as having a negative impact on self-confidence as well as on willingness to engage in social interaction. One participant referred to the stigma associated with unemployment, with jobseekers often referred to as “dole bludgers”. The jobseeker with a mental health condition was seen to be subject to the dual stigma associated with unemployment and having a diagnosed mental health condition.

There was evidence that some people avoid work altogether due to fear of workplace rejection, preferring to associate with others in a similar situation:

A lot of people are afraid of people with schizophrenia too so they’re afraid of that rejection, you know. When they go places, if someone knows that person’s got schizophrenia then the other people in the workplace are gonna [sic] be scared of them, don’t want them there...and that is a real thing that still a lot of people don’t want those type of people around....so people just think, well, it’s easier to

stick with staying home or hanging out with friends who also have schizophrenia.... (Peer worker)

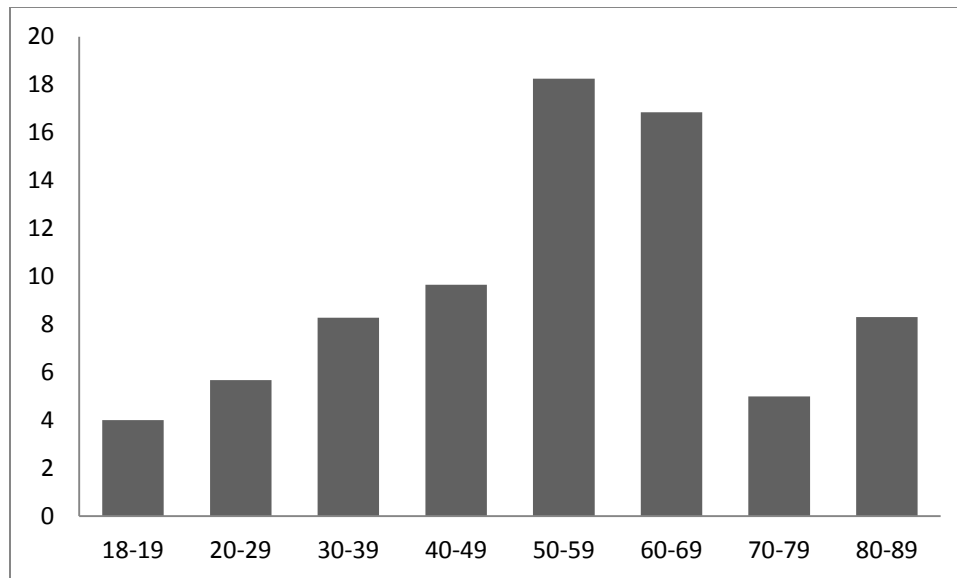
Others seemed to try to avoid stigma by seeking work independently without accessing government funded employment support programs:

...a lot of people want to return back to the workplace but they want to do it on their own because they don't want to be labelled with a mental illness going into the workplace. They've still got that stigma. They believe there's that stigma still there so they'll attempt themselves and probably do quite a poor job of trying to get back in the workplace. (Case manager)

Participants commented on how disclosure of a condition affects the regard people have for you, results in social avoidance and that co-workers "hold you at a distance".

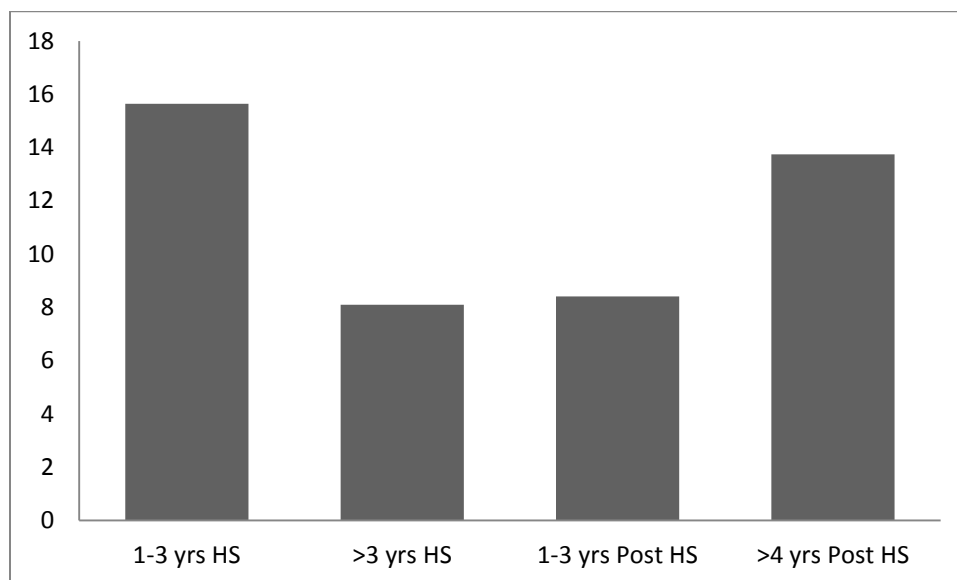
Workplace prejudice was perceived to make people feel uncomfortable and may cause them to leave.

Figure 31 shows the number of coding references to stigma according to age group. Average frequency of references to stigma was highest in the 50-59 year age group, however the responses of younger participants revealed an acute awareness of stigma among younger age groups.



*Figure 31.* Average participant references to stigma according to age group.

The highest frequency of references to stigma was among participants with 1-3 years of high school education (see Figure 32).



*Figure 32.* Average number of coding references to stigma according to educational level.

**Categorisation and labelling.** Participants noted the practice of categorisation and labelling people with these conditions and its deleterious impacts on work outcomes. An employment service provider observed, “...it’s very easy to pigeonhole people rather than treating them as you find them...” It was pointed out that some people choose not to use employment services due to concerns about disclosure, labelling and stigma.

Terms such as *disability* were in themselves seen to be incapacitating. Respondents talked about the impact of labelling on client expectations, self-concept and self-efficacy:

...you get people of fourteen and fifteen and they’re being diagnosed and stuck on a disability pension and all this medication and told “Ah that’s alright you’ve got...she’s got this”, you know. That’s the worst thing they’re really doing to that child and then the child’s expectations of what they’re capable of is just totally down. It’s like “Ah well I’ve got a disability”. If you’re telling these very young people “You’ve got a disability”, well, they’re going to act exactly like you’re telling them, and they’re going to be disabled and they’re not going to go and do these things. So I think that is a really massive thing, this early labelling of people as having a disability and giving them a disability pension. (Peer support worker)

**Negative stereotypes.** Negative stereotyping of people with severe mental health conditions was attributed to lack of education and understanding among the public and employers:

I think there’s some really bad stereotypes in the community around those conditions. People don’t know how to handle them or how to feel comfortable with someone with those conditions. (Employment consultant).

There was ample evidence of negative stereotyping regarding the character, performance, behaviour and recovery potential of people diagnosed with these conditions. Character stereotypes included lazy, manipulative and non-compliant. Performance stereotypes included less competent, unreliable, hard to manage and less productive. Respondents identified that double standards operate in the workplace:

...some employers say ‘Ah, been down that track and it doesn’t work, they’re unreliable’. Yet if a non-disabled person comes to Friday night and has a night on the tiles and doesn’t come to work on Saturday morning that’s normal behaviour for young people here... (Employment consultant)

Behavioural stereotypes pertained mainly to unpredictability, dangerousness and inappropriate behaviour. Among participants with more than 4 years post school education, the most densely coded references were to behavioural stereotyping and in particular dangerousness.

**Perceptions.** Perceptions, emotional reactions, attitudes, beliefs and expectations of various stakeholder groups also constitute potential barriers to employment.

***Increased Workplace Risks.*** Several respondents perceived that employment of people living with psychotic conditions would make the workplace less safe and in particular alluded to a risk of acts of violence towards co-workers. There was also a strong sense among employers as well as community members that employment of more people with severe mental health conditions would increase the risk of work-related litigation including occupational health and safety and anti-discrimination claims.

Others, however, considered that the public safety would be enhanced due to having fewer people being “at a loose end” in the community.



***Employer Perceptions.*** Employer perceptions focused on business priorities, perceptions of employee capacity, business risks and capacity of businesses to accommodate workers with psychosis. Respondents repeatedly stated the main priority of a competitive business is to make a profit and that employers do not necessarily view it as their responsibility to employ people with these conditions. Mental health conditions were seen to do less for an employer's corporate image than employing people with other types of disabilities:

It would be a very big challenge I'm sure because mostly private companies would want some sort of public recognition as part of their PR exercise and then would they really want the public to regard them as a great corporate citizen because they hired people with mental health issues?.....Probably not.

(Community worker)

It appears employers may receive more public recognition for their corporate social responsibility if they employ person with a visible disability, and that some conditions were perceived to be more "user-friendly" to the public:

P69: It looks good for an employer to be taking someone like that [Down's Syndrome]

P68: Nice little Down's Syndrome kid you know

P69: Because you know they're covering themselves you know as far as their EEO [equal employment opportunities] policies

P62: They're user friendly to the public

P69: Absolutely (Community members)

It looks good to have a Down's Syndrome person as your pit cleaner, you're doing something for society aren't you and you know these things do happen in society. Unfortunately, there are some people who are just unemployable in whatever capacity and that may be whether they're schizophrenia or bipolar or drug addicts or.... (Employer)

Responses frequently contained references to business risk assessment and employers who employ a person with a mental illness were seen to be introducing an "unknown variable". It was, however, pointed out that any risk assessment is likely to be uninformed due to employer ignorance. Respondents viewed employers in open employment as unwilling to take risks. Several participants, including clients and carers, questioned why an employer would want to diverge from the norm by taking the risk to try and accommodate such employees. Employers generally perceived people living with a psychotic condition as being a potential liability and weakness in the team. Some stated that it was not financially viable for them to employ people living with these conditions. Perceived costs for the business included increased cost of production due to reduced work rate and loss of productivity during episodic exacerbations, resulting in less profitability. Potential loss of clientele or damage to business reputation was envisaged as a result of inappropriate workplace behaviour. Potential risk of compensation claims was anticipated as well as litigation due to discrimination or unfair dismissal. Increased cost of insurance as well as additional time and cost involved in providing training, supervision and support were also foreseen.

Participants suggested that an employer's willingness to employ a person would be influenced by the type of work, the workplace and workforce, as well as the nature and

severity of the mental health condition. In relation to suitable work, some jobs were seen to be more “forgiving” than others. Participants considered that lapses in concentration, attention or errors could be dangerous, expensive or otherwise catastrophic in some jobs:

This guy used to occasionally sort of go off into limbo land and what would happen would be this thing [box] would get to the end of the production line and someone would pick up the box of biscuits and the arse would drop out of it. You laugh, but as I say he was dropping about thirty five dollars’ worth of biscuits at a time. (Employer)

Respondents suggested it is difficult for people with severe mental health conditions to gain entry into certain occupations such as the police, military and some professional positions such as teaching. Participants did, however, provide several examples from their own experience of individuals who, in spite of these conditions, had effectively maintained positions in the army as well as high level professional positions such as university professors, an accountant, registered nurses, a neurosurgeon and lawyers. One community respondent argued that having lived experience may even be an advantage in some occupations:

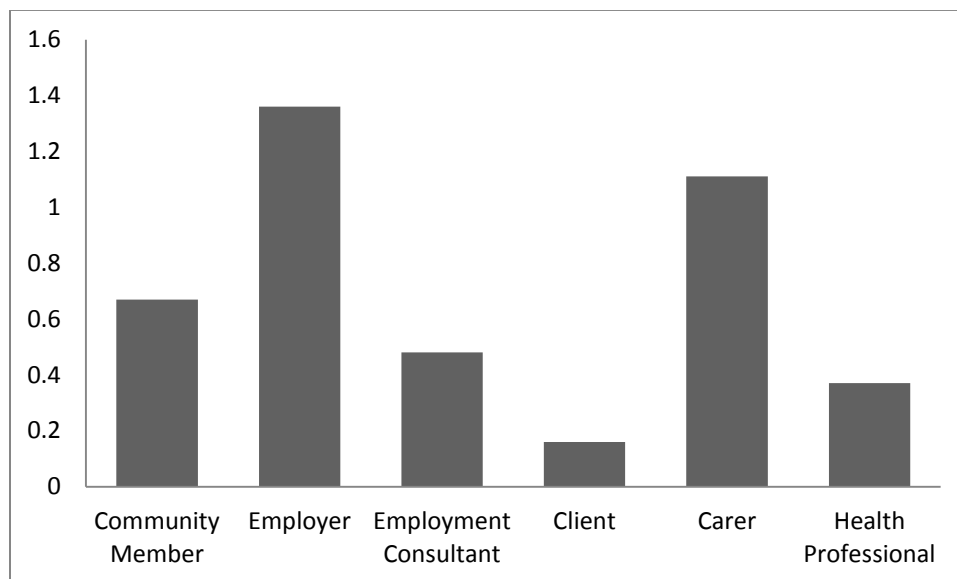
...but if you’ve got this condition and you’ve got it under control and for you to maintain a psychologist’s status or whatever you need to act normal in front of people and so if you are able to do that despite all the disease and everything surely your advice to people should be valued even more so than if you hadn’t had this disease because you have first-hand experience. (Community member)

Participants surmised employers would perceive employees as “hard work to manage” and that there would be additional effort and cost associated with putting

management systems in place to meet duty of care obligations in the workplace. In the words of one participant, “It’s easier [for employers] to take the person who’s upfront...bright and shiny...show him once and he knows how to do it”.

One employer inferred that boring, repetitive, menial jobs were fitting for such employees. The same respondent, however, acknowledged that some people with professional and trade qualifications may find it hard to get a job and become self-employed, while others work for employers who find them to be good employees.

**Emotional reactions.** The most commonly referenced emotion in this study was fear, often referred to as the “fear factor” or “fear of the unknown”. Figure 33 shows the number of references to fear according to stakeholder group.



*Figure 33.* Average participant references to fear according to stakeholder group.

One employment consultant openly acknowledged reluctance to work with people with mental health conditions due to past personal experience of a relative thought to have had schizophrenia. Although some employment consultants appeared to be comfortable and have a relaxed attitude towards working with people with psychotic conditions, other

employment consultants were seen to be fearful due to lack of relevant knowledge, skills and experience.

Clients were perceived to be fearful of stigmatisation and discrimination and in particular: employer questions about their work history; that disclosure will change the way they are treated at work; and being unwanted and rejected by others in the workplace. Other client fears included fear of failure and others' expectations; fear of relapse and possible need to take time off work; fear of returning to work following an episode due to judgemental reactions from others; and fear of losing the disability pension.

Community members were seen to be fearful of the unknown; the unusual; violent, aggressive and unpredictable behaviour; as well as their own sense of incompetence around how to approach, communicate and interact with people experiencing psychosis.

Employer emotions identified by participants were anxiety, fear and anger. Some employers appeared apprehensive due to past negative employment experiences. It was felt employers may have concerns about their ability to manage an employee with a mental health condition in the workplace. The primary emotion attributed to employers by all stakeholders was fear. Fear was also the emotion most commonly expressed by employer participants themselves. The degree of perceived employer apprehension ranged from being a "bit fearful" to "horrified." One client indicated that disclosure of a mental health condition may shock some employers: "...if the boss looks shocked and horrified you could just wipe it off and say '...of course it's nothing. I take tablets and I'm alright'". Employers were attributed with a general fear of "the unknown" and of

“mental illness”. Employers were also attributed with a number of work-specific fears including:

- loss of profitability due to employees requiring too much support and supervision; work attendance and productivity issues; unreliability and inability to perform assigned tasks;
- risk of relapse with need for hospital admission, time off work and impact on ability to maintain the position;
- an episode involving violence or aggressive behaviour, inappropriate behaviour or public incident;
- negative impacts on business and/or co-workers due to inappropriate or aggressive interactions with customers or staff; and
- potential for litigation and legal liability arising from occupational health and safety claims or unfair dismissal.

Some respondents also made reference to employer anger in the context of annoyance at unplanned absences from work and workplace bullying. Co-workers were attributed with reactions including fear, resentment and even concerns about possible contagion.

Analysis of relationships between nodes revealed that lack of knowledge, awareness and understanding contribute to fear and discrimination.

Health professionals expressed concern that factors in the work situation such as high stress levels, excessive demands or irregular hours could lead to relapse. They also expressed concern regarding the potential negative impacts of menial work and an artificially protected work environment on self-esteem.

Carers communicated feelings of hopelessness, despair and depression in relation to employment outcomes. A psychiatrist identified carers may experience guilt and feel: "...it's a big illness. Why must we make him work?" Carers also communicated anxiety about loss of the disability support pension as well as concerns about the psychological impacts of job failure or loss. Some carers were perceived to protect their loved ones from work due to fears around possible relapse.

**Attitudes.** Most frequently referenced attitudes were those of employers, co-workers and health professionals.

***Employer attitudes.*** Several participants alluded to employer prejudice. Participants felt employer attitudes are influenced by social stigma as well as the approach to treatment of these conditions:

...perception of the government's stance [on treatment] gets passed on through the whole community. So if the government's going to care for the mentally disabled in this manner, kind of just keep them out of sight and out of mind, I wouldn't want to employ someone like that. I'd just want to keep them in the back room, out of sight and out of mind, because it just filters right through."

(Community member)

A respondent indicated that having a family member affected by the condition may elicit more employer understanding and acceptance:

...we've had employers who are actually empathetic with some conditions...I can think of someone who had bipolar and didn't disclose and when the employer found out they said, "Oh if only we'd known we'd have understood and my sister has that condition". (Employment consultant)

Some employers reportedly develop fixed negative views as a result of past negative experience with a particular employee. However, an exception was cited of one employer who persisted with employing people with schizophrenia despite numerous adverse workplace incidents and misadventures. Attitudes were also seen to vary as a function of the attitude of co-workers and the employer's relationship with the employee.

Employers were perceived as becoming increasingly less sympathetic of inability to meet timeframes or the need for extended absences from the workplace due to unwellness. An employment consultant commented of an acquaintance, "...he would isolate [himself] for two or three weeks at a time, just lock the house and not go out and that was his coping mechanism and *no employer will wear that.*" Respondents also suggested that employers tend to have less tolerance for absences due to mental health reasons compared to physical illness. Several participants identified that physical health conditions typically elicited more sympathy and willingness to make accommodations.

...it's to do with the stigma but also I guess being sympathetic cause if somebody had cancer...then you'd say "Oh that's really bad...oh take all the time that you need." Then if somebody had, "I've had a relapse of schizophrenia and went to hospital" they'd be like phew...a bit of a loose cannon... you're not coming back...." (Health professional)

A client participant described employer attitudes in the following terms:

...their attitudes are semi-caring I guess you'd say but they're not fully understanding of what's going on and they won't bend over backwards to help you. Like it would come to a point where....alright in my last job I didn't run out of sick pay or anything like that but they were still sick of me having the odd day



off. I mean I was pretty good. I was loyal to them and I worked hard but they still....he said something about it one day and I just said well.....so yeah....average (laughs). (Client with bipolar disorder)

Employer attitudes appear to be mediated by personal values and qualities. Carer participants felt an employer would need to be a very special person, have a heart for it or perhaps have known someone who experienced it. One participant commented: “You would need an employer with a huge social conscience who is that interested in his employees. I haven’t had any.”

***Co-worker attitudes.*** Co-worker attitudes were also deemed potential barriers. Participants suggested fear of the unknown may cause co-workers to treat an employee with psychosis differently. Co-workers may feel uncomfortable, be resistant or reject such a person:

She’s been there about four months and still the people [co-workers] tease her and they’re all young. Everyone’s only twenty and they don’t talk to her and include her and it’s sort of mean in the workplace but the employees just don’t mesh well with her. They just don’t want to have anything to do with them because they’re so different. Like this lady once tried to interact but some people just laughed at her and walked away from her and that puts the boss in a position because he has to say, “Okay, well you can’t treat her like that”. And that makes the boss look bad, and the employees get grumpy because they like teasing each other...

(Community member)

Another participant referred to resentment from other employees who may consider the person a liability and feel they will need to assume an additional workload if

their co-worker becomes unwell. The invisible nature of mental health conditions may cause co-workers to question the veracity of their condition and become less tolerant of absences from work:

In a physical illness you can say, “Oh they’re not here. They broke their arm. They’ve got to go to a doctor” and you can see that. But you don’t know what’s going on in their head. You personally don’t know if they’re lying or if they’re telling the truth or what’s going on or how extreme it is. You can’t tell.

(Community member)

Respondents felt that having to work with a person with a mental health condition may place additional stress on co-workers due to challenging interactions, increase in their workload due to unplanned leave and possible adversely impacts on their leave arrangements. It was felt that this may lead to feelings of jealousy and cause co-workers to become meaner towards them, especially if they are unaware of the person’s struggles “behind-the scenes” to maintain normalcy during working hours.

A student felt there was potential for co-workers to act negatively towards an employee with psychosis in the workplace:

I think other people would learn to be a team player or it would not function at all and they would blame everything on people with the conditions and it would just fail disastrously. Either one or the other. When you work together I think you learn stuff from each other or you just hate each other... If you do learn things from each other you would learn that, even though people have conditions where they could not work all the time or be productive all the time, you could pull your weight and help them out and this would benefit everybody. Or people would be

like why am I doing this? I don't deserve to help them and they don't deserve my help and I'm not going to do anything. Act out. (Community member)

A client respondent indicated that co-workers may tease you: "Work mates... they know you got a disability, they take it out on ya and they pay out on ya and so you just don't want to be there". A young respondent related this experience of co-worker attitudes towards an employee with a psychiatric disability:

She loved coming to work. She was always early. She was so excited but it was still a tough situation because when everyone was being really mean to her at work, you can't really have that in the workplace. Everyone needs to respect each other and no one ever did so it really did put the bosses in an awkward situation-like you've got to be nicer to her it's not her fault. (Community member)

An employment consultant also referred to the potential for workplace bullying if an employee is perceived to be less focussed or capable than other workers, particularly in "full blown bloke environments, factory environments, manufacturing environments".

Lack of social acceptance in the workplace was attributed to lack of staff education:

...quite often it can be that a manager or an employer will think it's okay but they don't perhaps educate their...employees and then someone with a mental health condition can have a hard time...socially like in the lunch room and, you know, putting stuff into their lockers...and that doesn't always come to the fore until further down the track. (Employment consultant)

A client respondent referred to having been the victim of name-calling in the workplace and suggested this was more likely to occur following a disagreement with a co-worker.

It was predicted that workers who do not behave according to social norms may be ostracised by co-workers. On the other hand, another respondent felt it would be unfair for an employer to expect co-workers to overlook negative or behaviour that disrupted the social dynamics of the workplace. There was also evidence workers with a mental health condition who behave in a respectful and friendly manner towards their co-workers may nevertheless be ignored and disrespected by them:

...this lady she never had outbursts or anything. She would just keep to herself, always a smile on her face, always nice to the customers but when she was washing dishes and the person working in the drive-through right next to her tried to talk to her the other kids didn't talk back and would just like [say to her], "Oh keep quiet". (Community member)

Respondents expressed concerns about the possibility of judgemental attitudes from co-workers arising from lack of understanding, workplace mistakes due to their state of mind, or manner of interaction with other staff. Other respondents pointed out lack of self-confidence and paranoid thinking can result in disturbed communication and affect relationships. The most overt examples of prejudice among co-workers cited in this study involved young workers. One young participant suggested younger co-workers may lack the maturity to understand and respect such a person.

A client participant commented co-worker prejudice may be associated with being on a disability support pension. Participants predicted prejudicial attitudes in the workplace would have a major impact on an employee's productivity as well as make people feel uncomfortable and be less willing to remain in employment.

There were, however, also instances of positive acceptance and support provided by co-workers. Positive co-worker attitudes were reported in situations where the employer was supportive; where the co-worker had experience of a family member with a psychiatric disability; and where the person had an existing positive relationship with the co-worker prior to disclosure of the condition.

***Mental health professional attitudes.*** Health professionals were also perceived to hold stigmatising attitudes towards people who had experienced mental health problems. A peer support worker commented that “unfortunately some of our most stigmatising people are professionals, of all people, you know, that work in mental health that should know better.”

I went for a job once and I saw the RN [registered nurse] that I’d worked with at XXX and we had a bit of a chat and she would have talked to the nurse manager and I didn’t get the job and I’ve never *not* got a job before...so I knew she would have told her I was bipolar. (Client)

There was significant variability among mental health professionals regarding their perceptions of whether people living with a serious mental health condition want to work and whether competitive employment could be considered a realistic goal. While some were very positive and supportive of the concept, the views of others could be described as pessimistic, paternalistic and protective:

...from within the health professions, in regards to the potential for people with serious major mental illness to engage in the community and engage in meaningful activities and work, that attitude might be something along the lines

of, this person has a major mental illness therefore they can't work...

(Psychologist)

There was a perception on the part of some clients that they were ridiculed and humiliated when they claimed to have work skills:

P53: Just on the public system again, often they don't recognise your skills.

P54: They actually mock you if you say you have skills

P53: They do.... (Clients)

One clinician, a registered nurse, symbolised his cautious attitude to employment in this way: "...who knows what they're capable of and we shouldn't hold them back. Also we shouldn't throw them into the lion's den as well..." Some mental health professionals seemed uneasy regarding the intentions of government and considered that *pushing* a client who was not ready to work would be detrimental. However, when asked how they would determine whether a client was ready to work some health professionals did not appear to have seriously considered this issue. Health professionals also expressed concerns regarding peoples' capacity to pace themselves in terms of their working hours and the risks of relapse associated with attempting to work too many hours. The approach of health professional appears to vary in terms of the importance attached to work and how actively they would encourage a person to work. At one extreme were clinicians who questioned whether it was necessary for people to work at all. Then there were those who recommended a laissez-faire client-directed approach in which a decision to work would be left up to the client. At the other extreme were those who were more directive and considered return to work an important goal of recovery.

On the other hand, a client questioned the medical profession's right to determine their ability to work: "Well maybe we should ask why do the doctors have the power to decide how many hours people with mental illness should be working...like they're God or something." A businessman used a similar idiom to portray the attitude of psychiatrists: "...psychiatrists seem to think they're... sit on the right hand of God somewhere..."

***Client attitudes.*** Some clients, aware of the possible need to disclose and potential impacts of rejection and discrimination, were perceived to avoid job-seeking altogether (see also motivation section). Some clients were seen to use self-stigmatisation as a means of work avoidance.

***Carer and family attitudes.*** An employment service provider stated that carers of young people tend to perceive work as a means of normalising the life of the young person. Respondents observed that carers of young people were often keen for them to work, although reported lack of outcomes from job-seeking efforts:

I think most of them, especially if it's for young people, they're very keen for them to work...but I find, the ones I can think of, they all seem to hit the same kind of wall. It was just, "He wants to work, he's looking for work...but nothing comes from it" and the support there does not seem to match the need. So the employment agencies, whatever's available, doesn't seem to add up. (Psychiatrist)

***Community attitudes.*** Community members considered past incidents involving police shootings, although in the minority, significantly influence public attitudes and willingness to employ people with these disorders. In the words of one participant, "the mud sticks". Participants also questioned how community attitudes could be changed:

Unless you have education across the board you will never get rid of people's prejudices. Like no person with schizophrenia is going to get to babysit my grandkids in a child care centre. It's not going to happen because I don't...I'm scared of them. I don't know what they might do. How do you get rid of that prejudice? How do you train me to accept that person to be capable of caring for an infant that won't stop crying? How? (Community member)

An employment consultant acknowledged an initial reluctance to work with jobseekers with mental health conditions adding "I was frightened". A community participant perceived employment providers as quick to discount people with any sort of issue while a client participant said, "I just got a feeling that they couldn't care less basically...I was just another number".

**Beliefs and expectations.** Participants indicated that client beliefs and expectations in their recovery potential and capacity to work may be influenced by negative messages and lack of hope from those around them including society, family, treating clinicians and employers. A psychologist reflected, "Sometimes...all that hope and energy and plans they had for the future can be greatly altered by beliefs around their future recovery potential." It was suggested employers, along with clinicians, family and society in general, do not give people the message that they actually *can* work. A psychologist suggested that clients may be conditioned by others to think they can only do a certain amount of work. Participants suggested that clients may, due to past negative experiences, believe that people won't understand their issues and expect to be judged if they enter the workforce or return to work following a relapse. Responses indicated that due to stigma clients may also expect to have limited prospects for career advancement.



The most referenced beliefs and expectations were those pertaining to employers, mental health professionals and carers.

***Employer beliefs and expectations.*** The relationship between an employer and an employee was perceived to be a business relationship quite different from friendship, being less personal and more productivity orientated. The relationship was characterised by the following expectations: employers expect people to be there to do the job; attend work on a regular basis; to complete work tasks within reasonable time-frames; consistently conduct themselves in an appropriate manner; and to pull their weight in terms of the group. It was contended an employer expects to make a profit and is unlikely to employ people who cannot fully function or need to attend regular appointments with doctors or psychologists during their work schedule. It was also perceived that loss of employment may result from an employee's inability to return to work within employers' time-frames, inability to perform work duties, lapses in work performance or frequent or prolonged absences.

Participants commented that jobseekers are often expected to fill out a form or otherwise disclose they have a mental illness. It was pointed out that the absolute nature of declarations required on these forms belies the fact that people are variously affected and may effectively manage their condition with minimal functional impacts. Some participants were unsure whether employers can enforce disclosure as a condition of employment, however one employer clearly indicated he regarded false declaration of mental health status as a dismissible offence.

Employers were perceived as having a tendency to assume that employees with these conditions would be unable to fulfil their duties to the same level as someone

without a mental health condition: be less skilled, less reliable, have lower work rate, be less productive, have lost previously acquired skills and abilities and be more likely to cause problems in the workplace due to inappropriate, erratic and/or unpredictable behaviour. It was observed that employer expectations in relation to behaviour may be influenced by general beliefs about the relationship between mental illness and violence and crime. An employment consultant reported an experience with a potential employer who appeared to have no reservations about asking whether the prospective employee would come into work with an axe. It was expected they would take longer to train and adapt to the workplace, require more support, and that non-compliance with medication would affect ability to follow directions and complete tasks. It was also suggested that some employers might presume an employee who appears to be ‘dull and slow’ due to ‘dampening’ effects of medication is less intelligent. Employers were also seen to expect that an employee with psychosis would experience episodes which would affect their ability to work. Employers were seen to lack confidence in the capacity of people affected by psychosis to sustain employment and would be “waiting for the day that something is going to happen.” It was also mentioned that employers, due to lack of understanding, may have preconceived ideas and once they become aware a person has a mental illness, may look for problems and interpret certain behaviours in such a way as to fulfil their expectations. Employers expressed the views that “some of these people who are severely affected are unemployable”, that some really should be in a sheltered workshops, some can function adequately in boring, repetitive jobs and some are well enough medicated to actually work in the general work environment.

An employer with experience employing people with schizophrenia pointed out that employers tend to have generalised expectations of people with mental illness whereas all employees should be treated as individuals:

We, as employers, ...tend to talk about the negative side of business. We have unreliable staff and dishonest staff but there are a heck of a lot of good ones too and like anything you've just got to find them. So whether someone's got schizophrenia or they haven't you can get good and bad in both. (Employer)

Responses revealed employers might expect that employing a person with a mental illness would involve additional management responsibility such as supervision of medication, managing other staff members due to issues arising from workplace incidents, workload issues or prejudice, as well as a need to accept business risks associated with expected lower profitability and higher risk of litigation.

These general expectations were, however, contested by participants, who cited examples of people functioning in high level professional roles. An employer participant also pointed out that often people will produce or perform at a hundred percent when the condition is well managed.

***Co-worker beliefs and expectations.*** Participants described how co-workers may experience difficulty in establishing reasonable expectations of their work-related abilities and may overcompensate for colleagues with psychosis:

I think sometimes people can also be too sympathetic about conditions, like over-explaining things or like over-attentive to their needs or just in general that could kind of disrupt work...and then they would start making excuses for him that are not really related to his condition....you couldn't expect the same things from a

person without a condition than you would with one and so after a while the line becomes kind of unclear. You don't know where to draw the line. Okay this is because you've got the condition. I can allow that whereas this I can't. It kind of gets a bit blurry after a while... (Community member)

Other participants expected that employees with psychosis, due to lack of social skills, may fail to meet the social expectations in the workplace or may misinterpret social situations, resulting in ostracism by co-workers.

***Mental health professionals.*** The beliefs and expectations of mental health professionals regarding clients' capacity to work were perceived to be influenced by historical precedents:

I think in both the medical and the psychological profession we know how serious bipolar and schizophrenia are. If we go back thirty years ago they were institutionalised...now that we put them into the community, has our attitude changed enough to say that they can do anything more than live independently? Can they actually get a job as well? So...our own personal psychology gets in the way of their recovery... (Psychologist)

Some clinicians believed the expectation of employment is too high and maintained clinicians should rather be guided by the individual client's personal wishes and desires. They were at the same time quick to point out some clients seemed to lack motivation and goals. On the other hand, there was evidence clients had higher work-related expectations than clinicians:

...at a deeper level, we're probably all kind of looking at these guys and going yeah you want to go back to work but really you're probably not going to be able

to...it's not going to happen for you. We kind of give up a bit even though the poor old patient's still having a go at it. (Medical practitioner)

There was a wide variation across respondents in terms of their degree of conviction and expectations in regard to the work capacity of consumers, ranging from those who believed almost all consumers could work in paid roles to those who believed half their caseload would be incapable of paid work. There were also differences in opinion among health professionals concerning whether people could work if they had active symptoms. Some believed a person could not work while experiencing active symptoms while others provided examples of patients who were successfully working in spite of active symptoms.

Respondents identified clinician concerns about consumers' inability to cope with the pressure of job-seeking and employment. Health professionals were averse to any practices considered to constitute pressure or coercion to work. One health professional suggested the pressure of compulsory job-seeking with removal of disability support pension (DSP) benefits was more likely to result in relapse than voluntary job-seeking. It appears concerns about the potentially de-stabilising impact of employment often resulted in inaction.

Mental health professionals appeared to differ in terms of their understanding and belief in recovery.

We have some clinicians and bureaucrats who are fantastic and that really understand what recovery is...but there are other clinicians who are actually part of that whole process of making people feel more disabled by really giving them the message that ah well this is the best life's gonna [sic] get. I've actually

witnessed first-hand doctors, saying to them, “Ah well you’ve got to accept the fact that you’re never going to get better” and you know “well this is life”. I’ve heard people coming straight from university telling me that ah well [for] someone with schizophrenia, recovery is not real because people with schizophrenia have had ten per cent of their brain leak down their brain stem and they’re never going to get better and you just have to accept that recovery is not true...I’ve heard lots of clinicians say things along those lines that basically, no, you’re not going to achieve... (Peer support worker)

This was confirmed by a clinician, who attributed this belief to selective exposure to people who are acutely or chronically unwell:

I think there is a kind of belief that if you have schizophrenia you don’t recover and that’s a fairly pervasive belief. And within a mental health service we’re somewhat biased because we are seeing people with more severe mental illness whereas there will be lots of people with schizophrenia that actually are in the workforce but we don’t see them... (Psychologist)

There was consensus that recovery is a broad term referring not simply to recovery from an episode of unwellness but recovering a meaningful life. Although some proposed this could involve self-enrichment only, it was generally thought that this would involve some form of contribution to the lives of others. Some participants contended strongly this should not necessarily involve working for a wage, as voluntary work and caring constitute important means of enriching quality of life and contributing to society.

The impact of clinician beliefs and expectations on client self-belief was captured by this clinician:

... I guess when we work with them as clinicians I don't know that we give them too much hope in terms of that they actually can work despite those things. I don't know that that message really gets to them because I think that's the first hurdle for them, is them believing that they actually can work despite all those things that they are suffering from which are really serious and very, very hard to deal with... (Occupational therapist)

*Carers, family and friends.* The beliefs and expectations of carers, family and friends were seen to exert a powerful influence on client self-belief and expectations:

That thought never crossed my mind that having a mental illness would actually make you disabled in any way. That was not what I grew up with, ever...but I see, now that I've worked in mental health, that is what's told to a lot of people...

(Peer support worker)

Participants observed in some instances family members may have low expectations or actively undermine the person's belief in their ability to succeed and that the person may lack people to mentor and encourage them. One respondent observed some families may consider it acceptable for their loved ones to do nothing:

I see a lot of that going on where people are just like ah no, not wanting to expect anything, not wanting them to do anything. It's just like ah 'cause they might get sick again.....they're not too bad at the moment so let's just let 'em sit there. Don't encourage them or push them to actually achieve more...and I see heaps of that...and I just think well you're encouraging them to have this much life and personal growth instead of...it's this expectation that it's okay for you, and

healthy, to do nothing...we won't expect too much of that person. Just don't hassle them. Let them sit there for four years and do nothing... (Peer support worker)

Carers suggested that clients' work expectations may be unrealistic. Some families were even seen to actively undermine belief in ability to work:

I know a lot of people who have had, since they've been diagnosed with a mental illness, their partners and their families just actively saying things to them every day that's undermining their belief that they could actually ever succeed. Like "You'll never get a job. You'll never do this." Lots of negative stuff is put on them all the time and a lot of the times, the family and partners can act like ah yes we're caring but they actually undermine them all the time with the things they say about them as well. (Peer support worker)

There was evidence of discrepant expectations between carers and employment service providers regarding outcomes for younger clients. From the employment service provider's perspective, co-morbid substance abuse issues were seen to constitute a major obstacle to job-seeking for young jobseekers with these conditions. It appears that in the absence of work outcomes, carers seemed to lower their expectations and abandon efforts at further job-seeking. Employment service providers, as well as clinicians, appeared to be more influenced by carers when they considered that their careers were *not* work-ready.

**Self-stigmatisation.** A family member reported the impacts of social disadvantage on her relative with schizophrenia were such that he "thinks he is a second class citizen." Some client participants showed evidence of having internalised social stigma which was expressed in the form of self-stigmatising statements. A client with bipolar disorder employed in a responsible occupation said, "Well I mean it's, you know,



we're unreliable...your concentration might be reduced, your memory might be poor, you might feel like doing silly thing (laughs)...” Ironically, another client participant recalled how, when he jokingly said, “I’m a psycho and I’m proud of it”, this was met by severe sanction from his employer.

It appears that the sick role associated with being mentally *ill* may also be used by some as a means to avoid work:

....if they drop the disability pension and just go working full-time and then it doesn't work out, they have a big hassle to fill out whatever forms and get back on it and go through the job capacity [assessment], all that stuff again, whereas if they just say, “Ah no I can't work because it stresses me out” or “I get anxious” or whatever the reason they're giving, they get to sit on it... (Peer support worker)

**Taboo subject.** Several respondents referred to the taboo nature of discussions around mental health problems. It was clear from responses that mental health remains a taboo subject within families, schools, workplaces and in the general community. Several participants identified the effect of this taboo on information sharing and access to knowledge and awareness on this subject. There was, however, a sense of intergenerational differences and that young people are more open to talking about subjects previously considered taboo.

### **Discrimination**

Discrimination was seen to occur among employers, employment service providers, health professionals and in the community. Discrimination by employers was perceived to operate during the recruitment process in the form of unfair recruitment practices. Community participants considered it unlikely that an employer would

knowingly hire a person who is not “perfect” and said many people with mental health conditions will not even attempt to find a job because they know they may have to disclose their condition and be subjected to discrimination.

Participants described situations where employers were unwilling to employ anyone who might become depressed or was a bit different and jobseekers were declined employment without being afforded a reasonable opportunity to prove their ability. A disability employment consultant exclaimed “They’re the ones that want to work but they can’t work because no-one will give them the opportunity to get in there and show them that they can do what everybody else can do”. Particularly during times of high unemployment, employers were seen to favour people with an impressive resumé, strong employment record and no health issues whereas people with any disability or issues in their life were deemed to “come second rate”. Profitability motives and potential legal issues were used to explain why employers “don’t touch things like that” or “don’t step outside the square.” One participant commented, “I think the employers, if they knew that one of their prospective employees was going to have a severe mental illness, then stigma would prevent them from gaining that job.....”

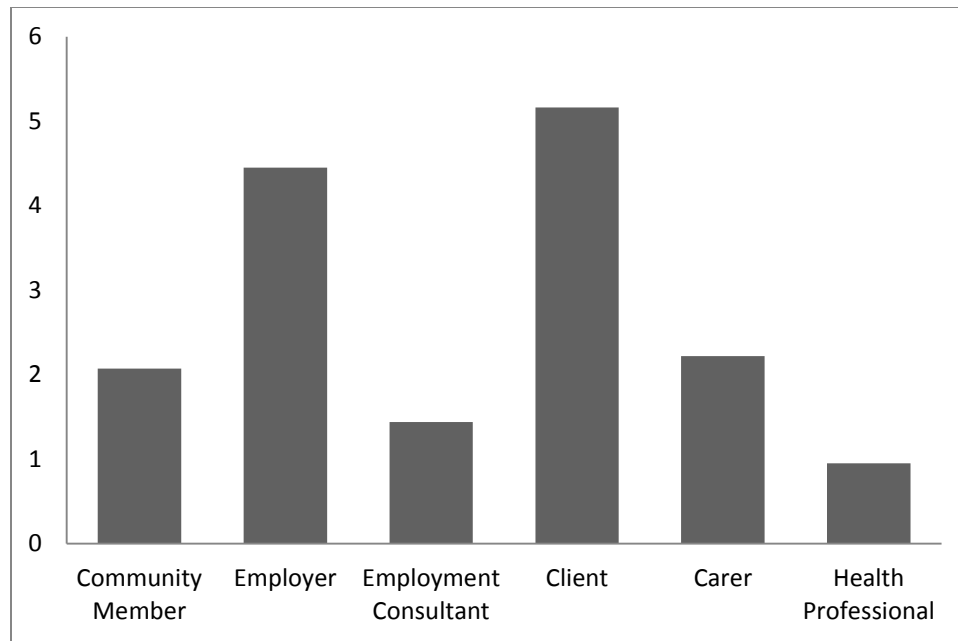
... she [jobseeker with schizophrenia] would be a fabulous employee, she really would. She’d love a job and we just would love to just put her anywhere. She wants to work in a factory or production line of some kind. She doesn’t want anything fancy. She just wants to earn a little bit of money but again it comes back to finding those employers and being able to educate the employers. That’s, I would say, the bigger barrier to us than the sufferers themselves... (Employment Consultant)

One participant who had been offered a placement found that when she disclosed having bipolar disorder the job offer was not followed up. She recalled, “I could see body language change when I told them I was a bit bipolar ...” A number of examples demonstrated attempts on the part of employers to screen out applicants with mental health conditions during the interview process. It appears some employers specifically developed these procedures following past negative experiences.

Discrimination during the course of employment was seen to take the form of lower wages, limited opportunities for advancement and various forms of victimisation. Victimisation in the workplace took the forms of rejection, bullying and harassment, humiliation, exploitation and unfair dismissal. One respondent described being viewed and treated differently in the workplace:

... after I’ve got the job they watch me like a hawk. And I’ve found a few jobs they actually bait me to see how I’ll go, whether I’ll go one way or the other. They’ll bait me to see what I’ll do... then she’d smile at me but she’d know it’d piss me off so she’d watch me react and unfortunately she got a reaction out of me and that’s how I lost one of my jobs. (Client with bipolar disorder)

A peer consultant recalled, “I did give them a letter from my doctor and information around the illness and that I just needed some time off but they just wouldn’t accept it.” Young people especially seemed very aware of the unkind treatment accorded by co-workers to people who are seen to look and behave differently. A youth respondent observed, “people are mean when someone’s different...especially their behaviour when they don’t understand why”. Figure 34 shows the number of coding references to employer discrimination according to stakeholder group.



*Figure 34.* Average number of participant references to discrimination according to stakeholder group.

Discrimination by employment service providers appeared to take a number of forms. These included reluctance to assist people with mental health conditions, questioning their work-readiness, and withholding assistance in circumstances where jobseekers do not wish to disclose. Employment service providers expressed the opinion that non-disclosure is not good for the industry, with one provider indicating unwillingness to assist clients who refuse to disclose. Employment service providers were sometimes seen to obfuscate the truth of their unwillingness or inability to provide assistance:

You go along there and they always say, “You’re not work ready”...Up in XXX this was happening to me all the time. I was going to a place [employment service], they’d keep saying to me “You’re not work ready. Let’s change your resumé.” They kept getting me to do better and better resumé...but the resumé

were of a very high standard. And I was saying “*Not work-ready?* Don’t you realise that I’m over fifty?” At this stage I was probably fifty two or so and I said, “I’ve worked in jobs. Don’t you understand that? I don’t have any problems. I’m just classified as having a mental health problem. And I don’t actually have any difficulties and when I’ve worked I’ve never had problems.” (Client with schizophrenia)

There was also an alleged lack of transparency on the part of an employment service provider:

I went to the [job] interview the next day and when I went in there they said, “Ah you’re *that* person are you? Two people have been sent by [employment agency]. It was the other one who was sent as the person to get the job. You were just sent here for the experience of being interviewed. Me coming here just for the interview? I’ve come all the way from xxx and we’ve been involved in a car accident so I could be here.” I was very angry about it...I felt set up by them [employment agency]. It’s pretty annoying when you’re actually on a holiday and they ring up and say you’ve got a chance of getting a job and there was *no chance at all*. They were lying to me. (Client with schizophrenia)

Health professionals were not exempt from perceived discrimination in the form of judgemental comments, undermining belief in work abilities and focus on a compliance model of treatment.

**Disclosure issues.** Disclosure of mental health issues in the workplace was a major topic of discussion for all stakeholder groups and in particular clients (see Figure 35).

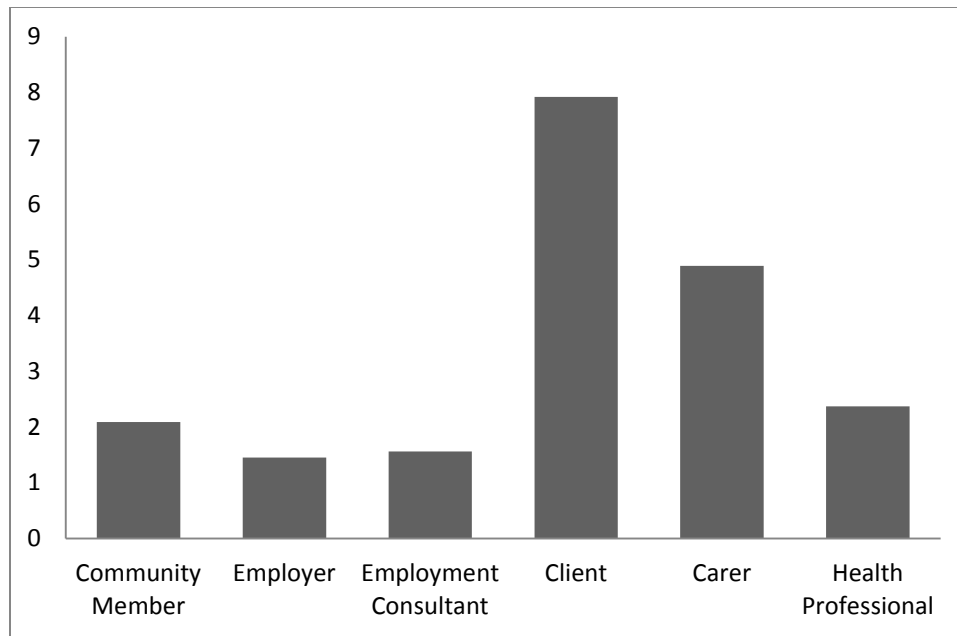


Figure 35. Average number of participant references to disclosure according to stakeholder group.

**Stakeholder expectations regarding disclosure.** Lack of openness about the condition was perceived to be a potential barrier to employment. Several participants from different stakeholder groups felt employees living with psychosis could not expect employers' compassion and understanding if they had not been "upfront and honest" with them. A community respondent also maintained co-workers have a right to know if employment of a co-worker constitutes a risk to their personal safety.

Employment consultants likewise considered disclosure a moral obligation and stated non-disclosure was not good for the longevity of the job or for the industry. Employment consultants were generally strong advocates for disclosure. Although one employment consultant indicated disclosure is not mandatory, another adopted the stance, "if you don't have disclosure, you don't have placement".

It was clear from the data that several respondents had sought advice from health professionals on this matter. Health providers felt people had a right *not* to disclose. A client participant with schizophrenia commented “....why you have to disclose I don’t know.” Clients and carers were clearly aware job seeking agencies and job application forms may require disclosure of their condition. A family member said that failure to disclose, talk about it and educate others would result in ongoing inability of others to understand and communicate with a person with a psychotic disorder. A community participant questioned the fairness of expecting people to disclose conditions and then discriminating against them on the basis of this information. It appears some participants, who would otherwise be unwilling to disclose a condition, may be willing to disclose in circumstances where having lived experience of a mental health condition is a condition of employment, such as in peer support roles.

Employers in the sample seemed to expect disclosure and one businessman considered an employer would be negligent if they *did not* elicit this information during recruitment. Some even considered that deliberate non-disclosure could result in subsequent disciplinary action including dismissal.

Paradoxically, one participant commented she had observed a job interview where a person had voluntarily disclosed a mental health condition during the interview and co-interviewers had considered the disclosure “inappropriate”. Given the conflicting nature of expectations regarding disclosure, it is not surprising that one participant, when asked to provide a job reference for a friend affected by a serious mental health condition, described feeling awkward about “hovering with the truth”.

*Individual differences.* There were diverse approaches among client participants to the issue of disclosure. Among those choosing to disclose, there were varying degrees of transparency regarding the nature of the condition, ranging from complete openness about diagnosis to more superficial descriptions of difficulties. Some individuals were described as “quite bold”, “very open” or “honest” about their condition. A carer, referring to her son with schizophrenia, said “...with the acceptance of people, he just tells them up front. He says, ‘If they don’t understand....if they can’t manage my illness that’s their problem...’”. Some client participants preferred partial disclosure, described as not divulging the “absolute truth”. This was attributed to fear that if they told the whole story they would not gain the job.

One employment consultant explained that the extent of disclosure was another difficult decision and would depend on client wishes and the demands of the work situation. There were individual differences in the circle of people to whom disclosure was deemed fitting, with some clients leaving this decision entirely in the hands of the employment consultant and/or employer and others deliberately seeking to confine disclosure to a limited number of management staff or co-workers.

Others try to defer disclosure until after they have secured a position. Deferred disclosure was seen as a means to avoid discrimination during the recruitment process and allow time for the employer to get to know the person prior to disclosure. Some participants reported deferring disclosure until they considered it necessary for the employer to know, due to treatment needs, onset of symptoms or following a relapse requiring prolonged absence from work.



On the other hand, some client respondents favoured non-disclosure. Of these respondents, some indicated they preferred not to use government employment services due to the perceived need for disclosure, and therefore approached private employment agencies or sought their own employment without accessing any form of employment assistance. It emerged that some people may avoid work altogether due to the perceived need for disclosure and associated stigma and rejection, preferring to stay at home or associate with friends with similar conditions.

Clients who preferred not to disclose their condition to an employer justified this position on the basis that: employers do not need to know; the information was not specifically solicited by the employer; they felt uncomfortable about disclosing; their condition does not impact their ability to perform the job, or that many people in other situations hide information they do not wish to divulge to others. The data indicates some non-disclosing clients, when unable to sustain work, would prefer to simply leave their employment rather than disclose their condition to an employer.

An employment consultant suggested non-disclosure may be due to denial rather than fear of stigma or discrimination. A family member provided yet another perspective, indicating her relative with lived experience of schizophrenia would never agree to *disclose* because he does not wish to be put “in a box” and, though acknowledging he is different, contends that we are *all* different in some way.

***Cost-benefits of disclosure.*** Although respondents identified benefits of disclosure in the context of employment, it was recognised non-disclosure also has benefits, and that both disclosure and non-disclosure carry significant risks. An employment consultant summed up the disclosure dilemma as, “You’re sort of damned if

you do and you're damned if you don't". A summary of participant views on the cost and benefits of disclosure versus non-disclosure is provided in Appendix L. The decision whether to disclose to an employer was generally considered to be a very difficult and stressful one. Disclosure of a mental health condition was viewed by some as being something very personal and private. The most common feelings associated with disclosure were fear, ambivalence, discomfort and embarrassment. The dilemma of having to explain absences to people who may have limited understanding of their condition was also identified. In particular, there was conflict around whether, when and what to divulge and possible consequences of disclosure or non-disclosure:

P69: Do I let those barriers down and tell the person and be honest because I may need to have periods off? Will that employer be willing to give me that time or am I cutting my nose off to spite my face by telling them, because I may not need any of that time off...?

P62: And if I tell them I might not get the job.

P69 That's exactly right. So I tell them and I might not get the job but if I don't tell them and I do need that time off they're not gonna [sic] be aware of it and at least if they do know there may be a little bit of leniency there but that could also backfire on me and not get me the job. (Employment consultant)

Another respondent expressed annoyance at the need for compulsory disclosure of conditions, which was experienced as intrusive and judgemental. Decisions around when, what and why to disclose were perceived to create dilemmas for any person with a serious mental health condition who is contemplating work. Participants described feeling a duty to tell their employer while simultaneously feeling a need for secrecy due

to perceived risks inherent in disclosure. A client participant said, “I’d rather tell them that right up front because I’ve always been upfront...that I am bipolar but I feel you get discriminated against...it happened to me”.

One employment consultant pointed out that the stress generated by such decisions can contribute to co-morbid depression:

They don’t know where they stand and that becomes very difficult for them to make good judgements and that’s when you start getting into the whole dual diagnosis, and depression starts becoming bigger than it needed to be initially because these are questions that they shouldn’t have to be stressing over.

(Employment consultant)

It was generally agreed that disclosure to an employer is a very difficult experience. There was evidence that both employees and employers find it difficult to have these discussions. An employment consultant stated, “...disclosure around those two conditions is always really difficult and touchy.” Furthermore, an employment consultant pointed out that disclosure to an employer or co-worker without provision of appropriate education can be of limited value in ensuring the provision of appropriate workplace support.

One participant, however, said that disclosure didn’t “phase” her as she didn’t see herself as different from anyone else. This respondent described a sense of relief following disclosure due to not having to fabricate stories to account for absences from work.

**Process issues.** One respondent living with schizophrenia remarked, “if you don’t [disclose your condition] it comes out anyway, your history comes out anyway, and if

you do people just have I think less regard for you or just hold you at a distance”. For some, efforts to avoid disclosure are thwarted by unsolicited incidental disclosure by a third party who has knowledge of their condition. This may occur during the recruitment process or during the course of employment.

It appears that client views on disclosure may change over time depending on past personal experiences. One respondent described becoming more cautious and wary of disclosure as a result of previous negative experiences with perceived recruitment discrimination and workplace bullying and harassment. In the process, some found themselves forced into fabrication to explain absences and deception to fill gaps in their resumé.

According to respondents, some non-disclosers will exhaust all their leave until the condition spirals out of control. Disclosure following a relapse generally seemed to have poorer outcomes. Some non-disclosing clients when unable to sustain the job simply leave rather than disclose their condition to an employer.

One employment consultant opined that non-disclosure with consequent job failure is not good for the employment service sector as it impacts employer attitudes and willingness to accept further placements. There was support for this position from an employer in the sample who recalled a negative experience after unknowingly employing a person with bipolar disorder. This negative experience resulted in more rigorous attempts on his part to screen out future job applicants with a mental health condition.

***Method of disclosure.*** In those cases where disclosure had occurred, some participants disclosed prior to employment during the recruitment process such as the resumé or interview stages, while others deferred disclosure until later during the course

of employment. Others contended that people who deferred disclosure until after employment could not expect compassion and understanding in the event of a relapse.

Disclosure could be intentional, unintentional, forced or unsolicited by a third party. “Forced” disclosure included requirement to complete a medical form or disclose information during an interview with sanctions for false declarations. Disclosure was sometimes unsolicited by a third party known to the client in other contexts or roles. Intentional disclosure of mental health care needs was perceived to be fraught with difficulty:

.... it’s like a hard taboo subject to talk about it and if you do talk about it, you say “Ah look I’m changing medications” and then they go, “Why?” and you go, “Ah well it’s because of this” and they don’t understand...it’s hard to explain to someone, you know, I can’t function... (Client with bipolar disorder)

Respondents pointed out that the method of disclosure itself can constitute a barrier, depending on *how* the disclosure is done. For some, who choose to be true to inner values and practice direct disclosure, the consequences for their career can be devastating:

...he never got a job and his father stood up at the funeral and told this whole story about...the terrible stigma that was attached to mental illness and how his son was unable to ever get a job because he always told the people at the interview that he had a mental illness. Now obviously the first thing we think of is why did he do that, but he was just that kind of person. He wasn’t going to make up a story. He just told them the truth. (Family friend)

A client cautioned, "...You've got to be really careful with the wording...when you go for a position." An employment service provider cautioned that employers tend to become wary if clinical terms are used due to prevailing negative stereotypes.

It was apparent that some people were uncertain of the extent to which their mental health status had been disclosed to others in the workplace and how many people were aware of their condition. One client participant indicated that in his view people would not want to "advertise" the fact of having one of these conditions, pointing to a need to clarify with employers the limits of disclosure. Participants acknowledged the difficulty faced by an employer in these circumstances, however, pointed to the need for employers to respect employee confidentiality.

***Ethical dilemmas in relation to disclosure.*** It was noted that disclosure might be a safety requirement in some industries where impacts of the condition or medication might affect aspects of work performance.

In a way you can understand the police and the military [but] I don't know so much about teachers. If they have an episode and there's a war on or if there's something going on within the police force and you can't rely upon that person... all the time. But, then again, quite often you can't rely upon a lot of other people (laughter) and they're supposedly normal. You know it's just the way you react to things. (Community member)

One respondent noted disclosure may be an ethical requirement in some occupations including psychology and some health related professions.

A community member also raised the difficult privacy issues faced by employers in relation to disclosure to co-workers. A conflict between right to privacy and concerns about public safety was highlighted in the following comment:

I think it should be allowed to be public knowledge and if someone with a mental disability wants to be employed they have to be willing to have it public knowledge because it's someone in your workplace's right...if there's a risk of them being stabbed in the head... (Community member)

The fear inherent in this remark is discussed in more detail in the section on stereotypes. There did not appear to be any guarantee of privacy in the workplace once disclosure had occurred, with clients expressing uncertainty regarding the extent to which disclosure of their mental health status had been further communicated to other third parties within the workforce.

Employment agencies appeared to consider it their right to freely discuss mental health conditions with clients, while employers spoke about measures and techniques to “force” disclosure such as medical forms and interview techniques.

P134...if I was conducting the interview I would certainly ask about it, because ...it's a growth area if you'd like to call it that...

P135: So many people on drugs who have...

P134: ...drugs and anxiety...

P135: ... mental...schizophrenia

P134: ...complexes and ADHDs and all this sort of stuff. If you're not doing that as an employer then you're really not doing your job properly. (Project Manager)

Furthermore, some employers seemed to consider that non-disclosure in these circumstances constituted a dismissible offence:

...if you provide a false declaration for employment then obviously it's virtually the same as taking money out of the till or anything like that...or going and saying that I'm a qualified accountant and you're not and all that sort of thing...so they're grounds for dismissal. (Employer)

Other participants, however, commented on the unfairness of situations requiring compulsory disclosure:

...with the job seeking agencies, you have to put down medical history and they do ask you about mental illness as well and what medication you're on. I would prefer if they didn't ask that...after I've put that down, even though I know I'm capable of doing the job easily, and I haven't heard back...I don't know whether that's why or not....I'm just assuming, but that sort of question feels very judging and invasive...they're not judging me on my ability to do the job. (Client with bipolar disorder)

The right to privacy was upheld by a health professional who commented:

Clients also have a right to privacy. They have a right to enter the workforce without disclosing that they have a mental illness and I don't think we should be taking that away from people. It's not always to people's advantage... (Psychologist)

Respondents also suggested, however, that disclosure can be misused at times as a means to gain leverage with an employer or put forward as an excuse for poor performance.



There was evidence that while some clients consistently disclose the whole truth about their condition, even if it is to their detriment, others may resort to fabrication and deception in an effort to avoid disclosure and that this in turn impacts their self-identity: A client with schizophrenia quipped, “I’m a good con artist when it comes to writing job applications. I’m a con artist, yeah...when it comes to that.” There was evidence that participants experienced inner conflict with personal values around disclosure and non-disclosure of mental health issues. This conflict was captured in a comment by a client with bipolar disorder: “I’ve found I need to be a little bit more cautious about who I tell...*although I’m a woman of integrity*...because some people judge you.” Another respondent who provided a reference for a friend acknowledged feeling awkward about knowingly withholding information from an employer.

### **Workplace Management Issues**

Interpersonal barriers identified in the workplace include management issues and impacts on managers of past negative experiences. Participants perceived a number of possible management challenges including managing co-worker relationships, employee performance and behaviour. Other potential barriers identified were management practices, lack of manager education and training and lack of workplace support. Two participants also commented on the lack of explicit reference to mental health in company employment policies.

**Management challenges.** Respondents considered psychotic conditions more challenging to manage in the workplace than physical disabilities because the condition is not visible, limitations may be less obvious and support needs less clearly identifiable. They were also perceived to be more difficult to manage than employees with intellectual

disabilities as functional capacity may vary over time due to episodic fluctuations.

Management challenges identified included managing relationships with co-workers, work performance and behaviour.

***Managing co-workers.*** Respondents identified difficult situations might arise with co-workers, placing demands on managers to manage co-worker issues. Adverse co-worker reactions mooted were disrespect, teasing, negativity (including playful putting down and horseplay) and ostracism. Participants felt managers may be required to manage inappropriate co-worker attitudes and behaviours such as social rejection, and workplace bullying and harassment.

Participants felt managers might also be required to manage potential impacts on co-workers. It was felt employers have a duty of care to protect co-workers and might need to manage co-worker complaints arising from challenging behaviour in the workplace, co-worker perceptions of excessive accommodations or inequitable leave arrangements and workload allocation issues. Community members suggested frequent absences from work may cause conflict with co-workers due to impacts on their workload and leave arrangements, and resentment at differential treatment afforded by management. One employer recalled having to manage a 'staff rebellion' over workload issues arising from erratic work performance on a production line affecting others in the team.

***Managing work performance.*** Participants felt managers may need to manage frequent, unexplained or extended absences from work arising from being unwell or need to attend appointments. It was expected there would be a need to accommodate work hours as well as for backfilling due to erratic attendance or unexpected absences.

It was envisaged managers would need to manage and accommodate altered states, fluctuations in mood or motivation and erratic work performance due to exacerbations of the condition or effects of comorbid substance abuse.

One employer, who had successfully employed a number of people with schizophrenia, indicated that their initial concerns were, however, unfounded:

...we were really sceptical. We thought oh gosh we've had some unreliable staff, that didn't have mental illness, and we thought gosh how's this going to be. And it was only that we didn't have to rely on them for our front position...that we thought ah give it a go because if they don't show up it's no big deal, so to speak, but yeah we were shocked how good it was. (Employer)

**Managing behaviour.** Participants also perceived that managers would potentially be faced with increased management demands such as coping with challenging behaviour, impacts of emotional outbursts or inappropriate behaviour in the workplace; abusive workplace behaviour, risk of damage to company property or damage to the reputation of the employee or the company. Related to this would be a need to manage customer reactions to avoid loss of clientele or business.

**Management practices.** Management practices were perceived to have a direct impact on employee well-being:

There were certain positions or times when I was at work and I just loved coming to work every day...it was a beautiful thing and then there'd be some sort of thing that would come down from management and it would just alter my view of how I felt about working. (Client with schizoaffective disorder)

Incompetent managers and poor management practices were seen to be stress-inducing. Participants pointed out that manager behaviours such as verbal abuse impact negatively on the mental health of *all* employees. Managers deemed uncondusive to job retention were variously described as: rude, “a tyrant and idiot”, unsupportive, rigid, inflexible, unwilling to make accommodations, and uncaring.

**Lack of manager education and training.** Participants felt that managers may lack understanding, training and relevant skills to employ people with psychiatric conditions. Respondents opined managers are inadequately trained to cope with the unique management demands of this situation. A business manager commented, “It’s all been self-education or asking for advice from people that know...”

Participants alluded to a lack of appropriate level of training and expertise for employers and managerial staff within organisations. None of the employers in this study indicated they had ever received any form of education or training during their business career on management of a person with schizophrenia or bipolar disorder in the workplace. Gaps identified in management knowledge include knowledge of what constitutes *reasonable adjustment* in the workplace for people working with a psychotic disorder, how to deal with someone with a mental illness, how to manage complaints from co-workers, the type of contingency plans that may need to be put in place and how to manage a psychotic episode if it occurs in the workplace. A paucity of management knowledge and expertise is demonstrated in the following quotes:

...if I got twenty people in here [this room] and said, “What is bipolar?”, I guarantee that I might be lucky to get one person who might know and so then

apply that across to the managers who've never had any sort of exposure...

(Businessman)

..then a friend of mine said, " Ah look he's got this [schizophrenia], you need to...we need to keep him on track" so...cause someone told *him* that that's what you should do. So that's (laughs) what we were going on. This is really good for people with schizophrenia, you've got to keep them on track. I said, "Okay" so I sort of knew then and could work with him...I was only a young guy then...but I could just sort of help keep him on track...and he was fine. (Business manager)

Participants identified gaps in personnel management skills relating to employment of people with bipolar disorder or schizophrenia including privacy issues, how to manage complaints from co-workers, stressors to avoid and how to manage an episode in the workplace. There was also a perceived lack of skills to manage perceived potential risks to the business. A community member stated, "I think employers are concerned that taking on someone with a mental health issue would lead to absenteeism, to perhaps episodes in the workplace. Many people are unsure how to deal with someone with a mental illness..." One participant had this to say about the training of managers:

...half the time you've got sixteen year olds controlling ten people working at fast food and they've got some cardboard cut-out Certificate III in Management and it really doesn't give them an idea of how to properly handle a situation like that, which in turn goes back to a law suit waiting to happen. (Community member)

It was felt failure on the part of managers to educate co-workers may result in social adjustment difficulties in the workplace:

...quite often it can be that a manager or an employer will think it's okay but they don't perhaps educate their employees and then yeah someone with a mental health condition can have a hard time... (Employment consultant)

**Lack of workplace support.** It was anticipated employees with schizophrenia or bipolar disorder would be hard to manage and, without support, considerable extra work would be involved. Participants foresaw the following increased supervision needs: supervision of medication; need for someone to watch and supervise; patience and understanding, and extra time required to train and fit in.

In situations where employee assistance resources are inadequate, the normal manager may be the first point of contact for human resource issues:

...if I have somebody comes up to me and says, "I'm not coping" you've got to refer them on to that scheme [employee assistance] but there's no-one there on site...it's normally left up to the normal managers to deal with these people in the first instance because they can't get an appointment to see the counsellor or psychologist until like next Friday and you have to go somewhere else...because all those spots at your workplace have been taken. (Clinical nurse consultant)

It was felt that there is a lack of workplace understanding and support, especially for people who do not disclose and are not linked with an employee assistance program. A client participant stated that lack of understanding and support, incompetent management or supervision makes it hard to work. A psychologist felt there was under-utilisation of psychologists in the workplace, purportedly due to perceived cost and lack of awareness of the role they can play in promoting a happy, healthy workforce. One respondent, who had unknowingly employed a person with bipolar disorder, reported he

had to obtain legal advice on an employment issue and felt there was a lack of support for managers. Participants identified a number of significant differences between work-related impacts of physical versus mental health conditions (see Appendix J).

### **Communication and Collaboration Issues**

There was reference to a lack of communication between the various sectors and stakeholders involved in achieving employment outcomes. Participants referred to a lack of positive, co-operative relationships and team work among agencies working towards common goals, particularly in relation to exchange of information (see also section on fragmentation of services page 237).

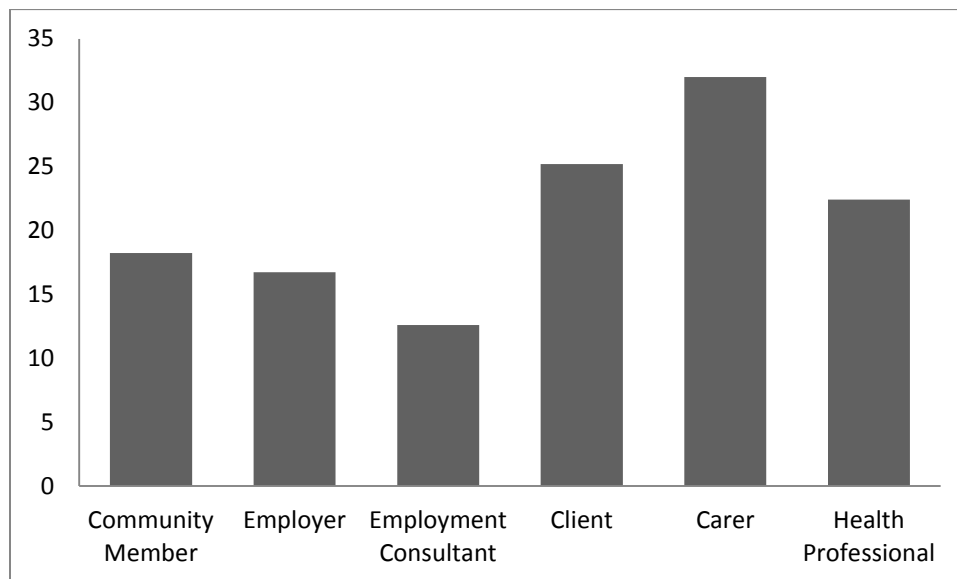
The manner in which information is communicated by health professionals was seen to impact on clients' hope, expectations and motivation in regard to their work ability. It was also suggested the type of work-related information provided to clients by clinicians depends on clinician expectations of their capability. Participants indicated the focus of communication may be on compliance and may fail to convey positive expectations, messages, information and hope to clients that they can recover and work despite the difficulties associated with their condition.

Several participants reported communication difficulties associated with explaining psychotic conditions to employers. Employment consultants referred to an inability to adequately explain to employers the cause of psychotic conditions. Client participants also reported difficulties communicating their experience to employers. A client participant expressed discomfort in explaining his condition to an employer saying it's "a hard taboo subject". He also identified a lack of suitable language with which to explain his inability to function: "I explained this to one employer. I tried to, but you

can't... it's your not being in your right mind...". Another client participant explained the difficulties inherent in deciding when and what information to divulge to a particular employer.

### Summary of Interpersonal Barriers

Interpersonal barriers were the most frequently referenced barriers to employment identified in this study. The most frequently referenced interpersonal barriers were stigma (1,217 references), discrimination (376 references), and lack of knowledge and understanding (359 references). Perceptions, emotional reactions, beliefs and expectations and negative stereotypes were major topics associated with stigma. Disclosure issues and employer discrimination were major topics of discussion associated with discrimination. The average number of references to interpersonal factors according to stakeholder group is shown in Figure 36 below:

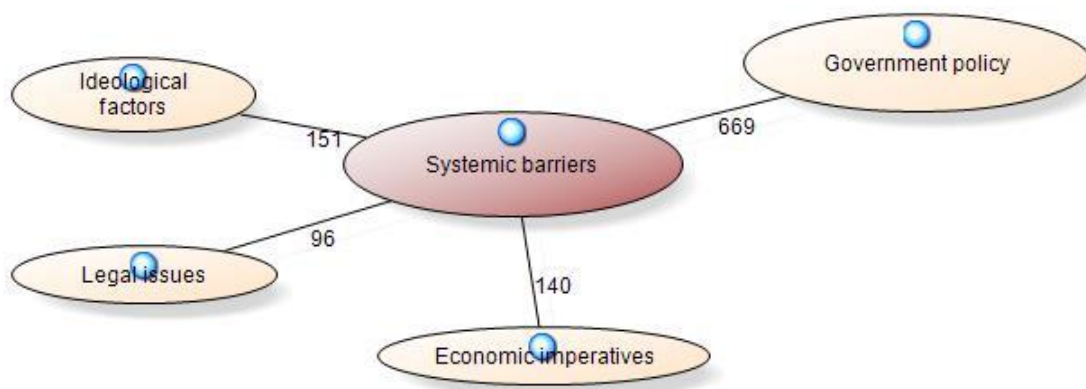


*Figure 36.* Average number of participant references to interpersonal factors according to stakeholder group.



## Chapter 10: Systemic Barriers

Systemic barriers were conceptualized as broader social issues which are beyond the control of a particular individual but which nevertheless impact on an individual's ability to find and sustain employment. Systemic barriers include economic conditions, government policy, ideological factors and legal issues. As can be seen in the Figure 37 below the most frequently referenced systemic barrier was government policy.



*Figure 37.* Summary model of systemic barriers to employment. The numbers entered adjacent to connector lines represent the number of participant references, or coding density, for each of the main barrier nodes.

A more detailed analysis of systemic factors as barriers to employment is provided in Figure 38. This chapter will focus on description of the contents of the most heavily populated nodes.

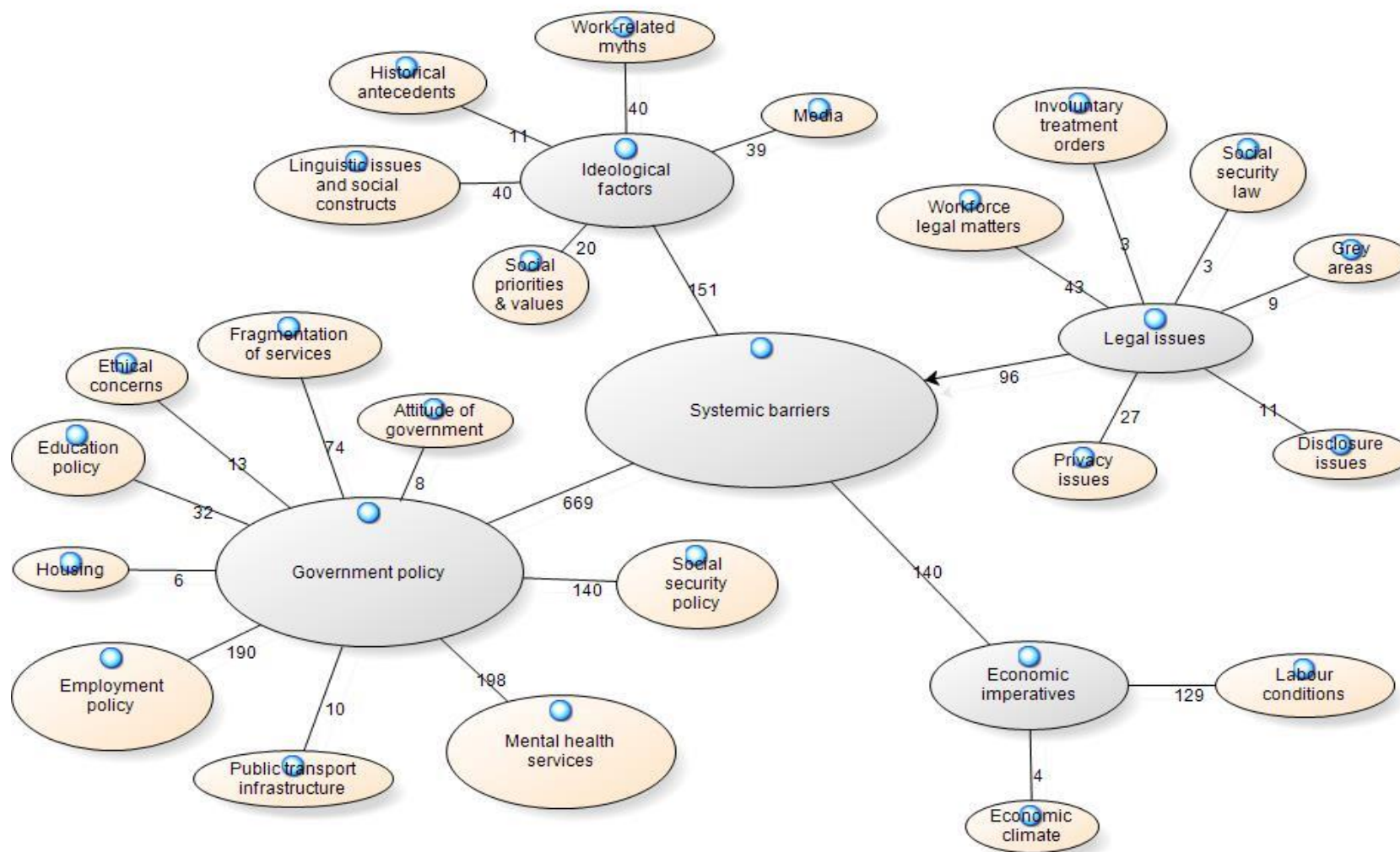


Figure 38. Second order analysis of systemic barriers to employment.

### **Economic Imperatives**

This section contains references to the impacts of contemporary economic conditions and labour practices. The current economic climate was cited as a reason employers may not wish to employ people who might need extra support. Respondents repeatedly pointed out that in competitive employment situations the main purpose of a business is to make a profit:

...at the end of the day businesses are there to make money. They're not there to help people. That's never their primary goal. When you look at charities and what not, sure. But as a business you're trying to make money. (Small business owner)

An employer suggested that *all* businesses discriminate in their own favour due to the responsibility of business owners to return a profit to share-holders. Business imperatives were viewed by employers as deterring them from employing people perceived to pose a high risk to the business. An employer explained, "...if you are a director of a public company you have a legal obligation to maximise the profit and returns for the shareholders, and that means to minimise risks of any form of threat to the business".

Participants pointed out that changing labour market conditions may impact opportunities to gain entry level work. An employment consultant pointed out that most of the factory jobs are no longer available and opportunities for "people who are a little different" are diminishing. An employer remarked:

P43: ...the number of jobs that are boring, repetitive and menial jobs are decreasing.....

P45: Right

P43: ...constantly decreasing because...

P45: ...manufacturing is drying up

P43: Yeah, yeah that's right. You gonna [sic] need a university degree to push the green button or the red button okay...

P45: Okay right yeah

P43: ... so these jobs are decreasing

An employment consultant, commenting on the increasing entry level requirements and increasingly competitive nature of job applications, said: "...you've got to have a certificate III to, you know, clean the toilets now. Fill out these lovely big huge selection criteria to clean the school toilets!" (laughs). Certain other characteristics of the modern work environment were also seen to pose a particular challenge for people living with psychosis including inflexible work structures, high stress levels and inability to control work flow.

Some respondents felt that, depending on the nature of the business, some smaller firms would be unable to afford to employ people with psychotic conditions due to a perceived need to multi-task. Some respondents indicated, however, that smaller firms were quite able to accommodate workers with severe mental health conditions and were better positioned to manage interpersonal relationships in the workplace.

### ***Workplace practices.***

A number of participants commented on the challenges of job-seeking, even for people in good mental health, with one therapist commenting "...even for the best of us it's a bit of a tricky situation going out and getting work..."

The inflexibility of current employment practices was seen as a major barrier for people living with psychosis. Participants referred to inflexibility around hours of work,

unwillingness to modify a previous work role or create a new role to suit the needs of the employee as well as unwillingness to accommodate periods of absence due to episodic fluctuations in the condition.

**Remuneration.** The remuneration offered to workers in sheltered workshops was questioned by several participants. Participants also commented on the supported wage scheme, which allows employers to employ people with disabilities at below award wages. One employment consultant indicated a preference to engage clients with mental health issues, particularly those with long-term conditions, under the supported wage scheme. Other participants expressed concern that *anybody* should be employed at below award wages:

I think it's wrong. If think that if you want to have equality and egalitarianism in your work team, you can't afford to have somebody who's doing a job and you're paying him X percent of the wages...so you're a lesser being than the rest of these so you're only going to get X percent of the wage. I think that's dreadful...what's the use of having an award, an award being the lowest level that you're legally entitled to pay, and then say, "Ah well that's the lowest level but this person is different so she gets X percent less than the lowest?" That's not right, not right.

(Businessman)

### **Government Policy**

This section reports on identified barriers to employment posed by government policies in the areas of health, education and employment. The most frequently referenced barriers were mental health services, social security policy and employment policy.

**Mental health services.** Mental health services were a major topic of concern to participants. A major theme of the carer focus group was the lack of significant change in mental health services over the years. Carers considered funding for mental health was disproportionately spent on medical services and that there was inadequate funding for community support services including provision of home support for people living with a serious mental health condition. A carer, comparing the resourcing of community support services for mental health with that provided in aged care, maintained that mental health is viewed “like the dirt of all illnesses”. The aspects of mental health services most commonly seen as employment barriers were diagnostic and treatment issues, access to mental health services and support, and communication and collaboration with employment providers. Most references focused on treatment issues including access, effectiveness and treatment approach.

***Treatment services.***

*Access to services and support.* The current public mental health service was perceived to be crisis-driven, with access to services and supports restricted to the most severe or acute presentations. A number of employment service providers reported feeling the weight of responsibility for supporting jobseekers experiencing difficulty accessing public mental health services. An employment consultant commented on the need sometimes to send letters to general practitioners on behalf of their clients requesting referrals to mental health specialists. Worker-friendly consulting hours and access to crisis support services were mentioned as potential barriers. Participants pointed out the difficulty for people with long-term psychiatric conditions of needing to attend ongoing specialist psychiatric consultations which typically don’t accommodate people

outside of working hours. A private practicing psychologist expressed uncertainty regarding whether people living with psychotic conditions are eligible to access psychological treatment under a mental health plan. Due to lack of support and appropriate treatment, some clients were considered to have sustained long term damage and “too far gone”, needing an extended period of time before they would be capable of working.

*Lack of support for carers.* Employment service providers as well as carers talked about lack of support for families including access to information, emotional support and respite services. Carers also commented on the lack of community support services for people living in the community with a psychotic illness compared to community services offered in aged care.

Several participants commented on the lack of care, support and opportunities for the families of people living with these conditions:

...what about family members as well? I mean who's supporting them? Who's educating them? Who's assisting them to then help support the member who is unwell. And, you know, parents often will ring here and partners and say I don't know what to do. I need some help. I don't know what to do. (Employment service provider)

Carers pointed out the psychological impacts of the caring role and the lack of support for their own mental health and relationships:

P85: ...as carers I mean how long have we dealt with it and how depressed do we get and how are we supposed to keep fighting to maintain our sanity and our own

health? And I've certainly looked around at a lot of people for ten years and seen people dissipating including myself.

P84: We've got to stay strong

P85: And partners....

P89: Splitting

P87: Well you don't have time for yourself do you?

P84: You lose your life. You lose your purpose.

P85: You're just discussing the same trauma.

P87: I haven't got a life any more.

P85: You don't go on holiday because when you're on holidays traumas happen when you're there.

P84: Well we can't. (Carers)

Although one carer acknowledged significant improvement in the recognition of carers over the past ten to twenty years, it was clear that carers experience significant unmet needs.

*Standard of treatment.* Several respondents alluded to inadequate standards of care in the public system. A community member commented: "...quite often they discharge people before they should. That's where the police shootings come into it." Carers commented that people are discharged from hospital without life skills to cope. Treatment issues considered to be significant barriers to employment included inattention to employment needs and overmedication. One respondent felt that quality of care was affected by insufficient attention to the quality of the relationship between client and case manager. This was attributed in part to difficulties attracting people to the field. It was



felt many nurses did not want to work in mental health and people may also be hesitant to perform volunteer roles involving mental health. Staff turnover was identified as another barrier to effective case management:

...unfortunately in the system there's a high burn-out rate so in my own son's case he would have a wonderful case manager and then suddenly she'd go somewhere else or be transferred or leave or she'd burnt out and someone else would replace her and he had to start all over again with the confidence... (Carer)

*Treatment model and approach.* Participants highlighted the current mental health treatment model as a potential barrier to employment. Lack of resources was considered a risk for difficulties accessing services, overmedication, early discharge and lack of recovery planning. The current approach to treatment was described as “strongly influenced by the medical model” and was seen by participants to be reactive rather than proactive. Respondents felt clients receive their medication but it “doesn't go much further than that”. A therapist referred to the recurrent relapses and re-hospitalisation associated with this model. Another described the approach to hospitalisation as “get 'em in, get 'em out” with lack of community follow-up to support the transition to work. Limitations in the efficacy of available medications as well as overuse of medication were cited as barriers to employment.

A number of participants felt the focus of treatment is on managing medication and that there is a lack of encouragement to work. Some clinicians apparently may feel uncomfortable talking about work in therapy or do not reach that stage:

...we do talk about work but we don't talk about trying to get them *back* to work....it is the final aim of therapy but I don't think we actually reach it. We are always sort of so much sorting out the other chaos. (Psychiatrist)

Psychologists seemingly prefer to focus on managing symptoms, with work viewed as an optional extra:

...where people are referred to a psychologist for intervention it's to help them manage their mental health condition but it also has this optional sort of add-on of helping them prepare for work...I have heard psychologists say, "I really don't feel comfortable focusing on employment with a client in a setting. I just want to do what I normally do which is assist them manage their condition." So it's an interesting question because it can be integral to someone's outcomes psychologically improving because without a job maybe things don't change too much in their environment or in their financial world and having a job can lead to changes... (Psychologist)

There was also a perception that staff in the public mental service may be too busy to recognise clients' skills:

That's a really serious problem with psychiatrists in the public system. They don't have time, they're just so busy. They don't have time to look at each individual person and what they might be capable of doing. (Client with schizophrenia)

Health professionals in the public mental health system considered themselves under-resourced to collaborate with other stakeholders with a view to achieving employment outcomes:

...we're hampered by time and pulling people in, getting the timing right with the doctor present, the other stakeholders present...some of these case reviews end up being only five minutes long...if you brought other people in, it could extend an hour and we don't have that time... (Registered nurse)

The treatment approach was seen to disempower people and result in a loss of self-confidence. Ironically, although clients are now de-institutionalised and receiving treatment in the community some clients of the community mental health service were described as “almost institutionalised”. A peer consultant commented: “I do see people within the service that now have almost institutionalised unfortunately”.

Several respondents pointed out that the perceptions and expectations of health professionals in hospital settings tend to be distorted because the patients they encounter are in an acute phase of their condition or those more severely affected, and they do not always have the opportunity to see how they function when they are well in the community.

Community participants questioned the extent to which patients are encouraged to work by their treating health professionals: “Like this one girl seeing a psychiatrist and all that. She's getting all that sort of help but is she being driven to work? Is she being encouraged to, you know [work]....?” It was apparent from responses of participants that employment is not a priority focus in mental health treatment. A psychologist observed: “...there isn't the same expectation or mind-set around achieving employment outcomes within the mental health professional areas.”

A politician pointed out that a focus on symptom management will not necessarily achieve satisfactory work adjustment or employment outcomes: “So health [services]

may...probably think by getting the person stabilised that gives them the opportunity to go further but on its own it's not going to do that." The most common issue identified by participants in relation to employment was an inadequate focus on preparing people for work or return to work following relapse. A psychologist and ex-disability employment service (DES) case manager opined: "...there's a foundation that needs to be there or the support needs to be there to enable that person to be able to attend work and do it successfully..."

Health professionals maintained that the current funding model does not recognise employment as a health outcome. One participant pointed out that funding for vocational outcomes has been taken away from health services and given to employment service providers:

I think we have lost the focus in terms of the fact that work is actually a health outcome as well. We have taken it away from health and given it to some other service and at the same time by doing that we have created a gap between health and other departments. (Health professional)

It was clear from responses of participants that treating health professionals have varying attitudes towards employment. Respondents referred to the powerful role of general practitioners in shaping work-related decisions. One respondent with bipolar disorder attributed her career success directly to the encouragement provided by her general practitioner. Others blamed their treating health professionals for not recognising their skills, readiness to work or unnecessarily restricting their work hours. Some participants felt the public mental health system did not recognise their skills or abilities.

There seemed to be no agreed on process for determining whether and when a person might be ready to return to work or even certainty or agreement between clinicians in what constitutes “work-readiness” in bipolar disorder or schizophrenia. There also seemed to be a lack of clarity on who is responsible for this form of assessment. It was intimated carers might also be involved in this process. Clinician opinion on this matter appeared to be influenced by carer opinion that a person was *not* ready for employment. The current approach of mental health services to the provision of prevocational support appears to vary depending on the professional background of the case manager. An employment consultant referred to the culture shock experienced by clients when confronted with the harsh realities and rigorous demands of job-seeking.

***Non-government organisation policy.*** For some clients, it seems the satisfaction derived from participation in funded community organisations was such they did not feel a desire to seek paid work. Several participants expressed dissatisfaction with the temporary nature of transitional employment opportunities offered by some non-government organisations. Others stated non-government organisations provide information but do not provide *real* support when it comes to employment. Clinicians expressed concerns about over-reliance on non-government organisations to support transition to work and felt they may not have the level of expertise required to transition people into competitive employment. One participant pointed out how the current model of funding community services results in multiple small services which are less cost-effective, incapable of meeting the full range of consumer needs, and seem reluctant to share ideas and resources with one another due to the competitive nature of funding opportunities.

**Employment policy.** The aspects of employment policy most referenced were employment services, and in particular the efficacy of support provided by employment service providers.

**Employment services.** The employment service program guidelines, compliance framework and key performance indicators were perceived to impact on work practices. One participant perceived that due to business demands, job agencies are very quick to discount people with any kind of issue:

...job agencies I think are very quick to discount anyone with any sort of an issue because they're in the business of getting work for people and because they get paid for finding work for people it's a lot easier to find [work for] able-bodied people... (Ex-employment consultant)

Another respondent perceived the funding model to be driving an inordinate amount of contact:

...these employment agencies were pushing so much onto the client trying to get them into...ringing them at inappropriate times and just freaking pretty much them out from heckling them so much so...it's not even taking that person's needs into consideration. It's sort of just "Oh, we just want to make money from this" so.... (Health professional)

Staff felt the amount of administrative paperwork detracts from quality time with clients, which was perceived as an important aspect of success with mental health clients. Some respondents felt that due to funding issues, insufficient time and effort was given to developing individualised resumés and to encourage and motivate jobseekers. A former

employment consultant said, “employment agencies because they’re run by the government have to do a numbers game...you’ve got to get so many jobs”.

*Prevocational support.* Employment service consultants often considered that clients were not work ready. A Disability Employment Service Provider commented, “We have a lot of people who are just not ready for employment.” An employment consultant had observed a lack of significant change following referrals to prevocational stream services. This provider stated clients love the idea of work whereas many were, in her opinion, not ready or inadequately prepared to meet the demands of job-seeking. Among young jobseekers with drug-induced schizophrenia, untreated substance abuse was identified as a significant factor mitigating against employment outcomes.

Employment consultants mentioned the importance of a holistic approach to employment with mental health clients, which may include attention to basic needs such as finding and maintaining stable accommodation, and linking with a general practitioner. There was a sense that extra time is required due to the often complex and wide-ranging nature of pre-vocational needs and the need to collaborate with treating health professionals and other agencies. One consultant felt the current referral assessment system does not adequately reflect the level of support needed by these clients. Employment consultants felt they are not trained or funded to provide the level of support needed by some clients. Some clients referred to them with lack of insight and co-morbid substance abuse issues were seen to be beyond their capacity to assist with employment due to the severity of unmet treatment needs.

*Effectiveness of employment services.* In relation to the level of service provided by employment services, one clinician observed that “nothing happens”:

A lot of them are on the disability payment I see and it seems to be they go and see the employment agency but nothing happens...and they call them back after six weeks. I can't see any proactive steps...that there's really something happening. (Psychiatrist)

Participants reported long waiting times or lack of follow-up from contacts with employment service providers:

I mean a lot of them, where the patient seems to be on the books, nothing happens for a long time...and then we had some feedback that they [employment service] say I don't *have* to work. It seems to be they go and see the employment agency but nothing really comes of it... (Psychiatrist)

Client participants reported varying levels of satisfaction with service providers. A client with bipolar disorder advised "... if you want to find a job in a reasonable amount of time you're better off on your own..." One client mentioned that he was able to find his own job quicker than going through a Disability Employment Service (DES) provider. It was apparent that some clients may prefer to use mainstream job network services or not to use government funded services at all, preferring instead to use private agencies.

Clinicians also expressed concerns about lack of understanding on the part of employment consultants regarding employment needs, and considered that in some instances their clients were being "set up to fail" by being placed into full time jobs which they were unable to sustain. Clinicians also felt that the IPS model of employment services does not meet the individual employment needs of all their clients living with a serious mental health condition and that some required a longer period of working with them or a more protected work environment.



Some concerns were expressed about lack of effort to provide an individualised resumé that adequately reflects jobseekers' skills as well as lack of effort to encourage and build their confidence. An ex-employment service provider described her experience of how an emphasis on numbers can detract from the quality of service provided by employment service providers:

... what I think is sometimes lacking is the heart...and I found that in the employment agencies as well. A lot of heart was missing. It was all about numbers and that hurt me. (Former employment service provider)

Employment service providers, for their part, sometimes felt like they were a “dumping ground” for people whose issues had been incompletely addressed by case management or prevocational programs. Employment consultants acknowledged lack of training in mental health yet find themselves becoming a point of contact for mental health crisis intervention:

... because you *do* develop those relationships, at the first sign of trouble in any area of their life, it's the employment consultant that they contact. We're readily available as opposed to trying to get onto mental health case workers or hospital or whatever so in a lot of situations we're the first point of call... (Employment consultant)

An employment service provider described her job as “a hard gig” due to administrative demands, need to multi-task and lack of understanding and skills to provide appropriate post placement support. In some instances, employment consultants felt morally obliged to “protect” long-term DSP recipients and “shelve and hide” people who clearly lacked capacity to comply with mandatory participation requirements. Employment service

providers referred to high rates of stress and occupational burn-out as a result of role demands. There was also concern expressed about lack of visibility and inconsistent practices among privately contracted employment service providers. Other points of discussion included resourcing of employment service providers. This was perceived to affect level of service capability and capacity, qualifications and training of staff as well as awareness of employment services among health professionals and clients.

*Staff skill level and training.* Several respondents considered that employment consultants may lack appropriate training and experience in mental health. Participants, including employment consultants themselves, stated that employment consultants may not be equipped with the depth of knowledge, understanding or expertise to effectively support people with mental health conditions into sustainable employment. Several respondents referred to a lack of suitable training for employment service providers. According to one employment consultant, “Nobody gets trained. They’re just thrown into the deep end...hope it works for you.”

In particular, respondents identified training gaps in terms of knowledge of the nature and client experience of mental health conditions, their difficulties in finding employment and how to respond and offer appropriate support:

I have found in my experience, because I’ve got a mental illness, that they don’t seem to be equipped or understand what sort of happens to that kind of person or what their difficulties are in finding employment. It’s like a whole ‘nother ball game than a physical disability... (Client with schizoaffective disorder)

Staff burn-out and turn-over were also raised as significant issues affecting service quality. Respondents expressed dissatisfaction with the amount of paper work

they were required to attend to, and identified industry remuneration rates and stressful work as important issues affecting job satisfaction.

*Individual Placement and Support model (IPS).* There was evidence of less than optimal levels of communication and collaboration between employment services providers and health providers in both the public and the private sector. Clinicians expressed confusion regarding their role in career planning vis-a-vis the role of employment consultants. They said that the model conflicts with the way clinicians work and what they attempt to achieve. The main drawback was perceived to be the focus on *rapid* placement with insufficient attention paid to the suitability or sustainability of the job. Clinicians expressed concerns that insufficient attention was given to planning a career pathway and finding suitable work that matches the client's capacity, skills, experience and expectations. It was felt that rapid placement into unsuitable work affects client motivation and the longevity of the job, and that inability to sustain the job impacts negatively on self-esteem. Some respondents felt that the IPS model does not meet the needs of *all* clients with a psychotic condition and that a percentage would benefit from other forms of employment support.

*Vocational assessment.* Health professionals especially felt the current funding model for DES services allows insufficient time and attention to be given to the suitability of work in terms of meaningfulness of work and clients' interests and goals, with consequences for the longevity of the job. Respondents noted that job failure has negative impacts on client self-esteem and willingness of employers to accept future placements. Participants felt that people placed in jobs mismatched with their personal interests, goals and capabilities would be less motivated to sustain the work. Some client

participants felt they were being pushed into jobs incongruent with their interests, abilities and values:

I find a lot of network support agencies try to shove you in any job...I had one try to shove me into telemarketing...I can't speak on the phone at all. I don't like talking to people on the phone. I've been shoved in a butcher's job...I love animals. I can't stand the sight of looking at animals that have been hanging put in the butcher's room... (Client)

A lack of cognisance of co-morbid physical health conditions and the need to match the job with the physical abilities of the jobseeker was also identified:

... the first job network agency I was with was hopeless. They just wanted to throw me in any old job. I'm with a disability network agency 'cause I've had two operations on my back...so I had to work out what kind of work I was going to do and unfortunately they kept trying to throw me in landscaping jobs and stuff and I said, "Mate, I can't bend down and touch my toes. How the hell am I supposed to landscape? I can't even use a shovel at the moment." I found that was difficult...I found the jobs on my own. They didn't find them for me. (Client with bipolar disorder)

Reference was made to the fact psychotic conditions may disrupt tertiary education therefore people who are very intelligent may not necessarily have the qualifications or experience to back it up and may be offered menial jobs which they experience as unstimulating and demeaning:

I went to [employment service company] years ago and said, "I want some work" and they said, "We'll take you somewhere you can work" and they put me with

all these people who were intellectually impaired and they were just putting letters in envelopes and stamping them and I was getting one dollar per hour. And then after two weeks they said to me, “What do you think of the job?” I said, “It’s horrible. I’ve been to university and you’ve given me one dollar an hour for doing this. I don’t want anything to do with it”. (Client with schizophrenia)

Employment consultants pointed out that the current funding model rewards short-term outcomes and there may be little concern about job suitability, impacts on the jobseeker or planning longer term career pathway or goals:

...in the new world it’s now all about turnover. It’s all about outcomes. It’s all about, let’s do it. Let’s get the person placed quickly. Let’s get the twenty, thirteen weeks, let’s get the twenty six week outcome and then let’s get rid of them. This will all crash and burn in the next two years I imagine once they understand that, particularly for mental health, this push, push, push is not gonna [sic] work. You’re gonna [sic] have people recycling through the system all the time. (Employment consultant)

It was suggested people may be encouraged to accept jobs that are not enjoyable, meaningful or stimulating to them and that this would also affect their motivation to sustain the work:

The last conversation I had with them [Disability Employment Service Provider] was that they had a job for me to put stickers onto ambulances and I was like... that’s not what I’m after...and that’s when I decided I’m gonna [sic] get on the phone and find an agency that looks like they’re going to help me. What I’ve come to realise now is that, that six months that I was with them has lost me so

much in terms of getting back into the IT workforce... (Client with bipolar disorder)

It was pointed out that individuals in a boring, irritating or depressing job might not want to go to work, in the same way as those who do not have a mental health condition:

...employment agencies, because they're run by the government, have to do a numbers game...you've got to get so many jobs. You've got to get this and that. And that to me used to upset me...they used to give them jobs that they weren't happy with and what's the point of that? They're not going to stay there."

(Former employment consultant)

Respondents commented that people with psychotic conditions are often placed in low status employment roles, which are often associated with minimal wage, less favourable work environment and conditions, limited prospects for career advancement, and may be experienced as degrading. Respondents referred to reluctance to re-enter the workforce at a pay or status level below that achieved before their illness and the lack of support for career continuity:

...with disability employment providers it's entry level all the way kind of thing. They can't seem to slot you into what you were doing before you became unwell. If I look at my past positions...I was unwell, yes, but I just needed to pick up that position again at some time later somewhere else or in the same company.

(Client with schizoaffective disorder)

*Post-placement Support.* Participants pointed out that the support from employment services is in *obtaining* work but that there is a lack of appropriate ongoing

support to *sustain* work. A carer felt this was particularly important for people with bipolar disorder and schizophrenia because of what she described as a “strong flee reaction” in the face of difficulties. According to carers: “that’s why jobs don’t last because there isn’t a keeper or a helper ...to watch, to supervise...to boost them.” An employment consultant observed, however, that on-the-job support “can be quite a demeaning experience for people” unless careful consideration is given to how this is approached.

*Employment service provider funding and incentives.* Employment consultants suggested the level of funding for mental health clients does not match the level of assistance required. One ex-DES manager felt that DES services were under-funded compared to mainstream job network services and lacked capacity and level of service needed to effectively assist clients with severe mental health conditions. Several respondents commented on the extra individual time and care that may be needed to meet the support needs of jobseekers living with psychosis. The current system of funding was seen to place too much emphasis on numbers rather than working closely with the individual. It was felt that many clients referred to DES have significant prevocational barriers yet the service has less funding capacity to address these barriers than other employment streams. A rehabilitation consultant commented, “...the funding levels are just crazy”. Employment consultants pointed out that, although they are not funded to provide general support services, they find themselves having to develop holistic case management plans for jobseekers and act as liaison between other fragmented services who do not communicate with one another, rather than being able to focus on assisting jobseekers to find work.

Participants observed that a huge bonus was payable for successful job placement of people with severe intellectual impairments, whereas there is no such bonus payable for placement of people with severe mental disorders who were considered much harder to place.

***Employer incentives and support.*** Some DES providers felt mainstream employment providers were significantly more competitive than disability employment services in terms of their ability to offer incentives to employers to employ their long-term unemployed clients. This was despite the fact that people with severe mental health conditions have often been unemployed for many years, and have greater support needs than mainstream jobseekers. One respondent felt employer incentives without the provision of appropriate employee training and post-placement support could result in unsuccessful placements with negative impact on employers' willingness to accept future placements.

***Employment opportunities.*** Lack of access to suitable work opportunities was identified as a significant barrier to employment for people living with psychosis:

In general society the perception of mental illness is *so poor* and there's such a lack of communication about it. That's why there's...has been now for years and years...agencies like ours, plenty of them, dotted all round Australia...but we would go through a hundred employers, maybe a thousand employers, to get one person to say yeah I'll give that person a go. (Employment consultant)

...a lot of the larger businesses or even government departments don't have a disability policy about employing people with disabilities. I know the local council was approached about having one implemented and he said, "Ah we're



not really in a position to do that at this point in time...it's something that we'll think about later on". (Client with schizoaffective disorder)

Several participants referred to the menial nature of job opportunities offered to people with mental health conditions:

I remember one of the consultant psychiatrists made the point because one of her consumers that was on her caseload was, you know those guys that collect the trollies?...she said, "Why is this the only job our consumers can get?" and I just thought actually that's really true. When you hear of consumers that have been previously employed quite often that will be on there [their case notes]. They do the menial jobs, or what people consider the menial jobs, that you don't really need a skill base or that you don't really need an education level. (Registered nurse)

Clinicians contended the Individual Placement and Support (IPS) model only fits a certain percentage of the population and that some people with mental health conditions require other approaches or pathways to paid employment. There were mixed views on the utility of sheltered workshops. While some clinicians and employment service providers viewed sheltered workshops as a "great stepping stone" to build skills, structure and confidence to return to the workforce, most participants rejected this option due to perceived lack of dignity associated with poor remuneration rates and low level work tasks. Client participants expressed resentment of sheltered workshops, which were described as "ghettos," and considered them to be demeaning and exploitative.

**Social security policy.** In terms of social security policy, social security benefits were the most frequently referenced barrier. Respondents recognised the importance of

social security payments for supporting vulnerable people, however, also commented on the “fine line” between benefits also becoming a barrier to employment. One respondent deemed it inappropriate to have been offered a disability support pension stating, “...they did try and put me on a pension....and I flatly refused. I said, “No why should I? I’m still capable of working”.

It was considered easier and less effort to just put people on the DSP rather than provide the counselling and support needed for them to obtain employment. There was a perception the system is geared towards proving that you cannot work, does not encourage people to work, and provides opportunity for some people to opt out of work.

The main issues were insufficient incentives for people on social security payments to return to work and disincentives due to deductions from payments and loss of entitlements on commencement of work.

***Lack of incentives to work.*** Social security payments were seen to remove incentive to work for some people. A psychologist stated, “I mean I’ve heard people say things like, ‘I couldn’t be bothered to go to work. I’ve got the dole why should I go to work?’”. A client with bipolar disorder remarked: “I know a lot of bipolar people that just don’t want to work ’cause they know they can just get a pension and they can be done with it.” Participants felt that boring, physically demanding and low paid work provided insufficient incentive:

It takes a lot of energy to get up, get organised, get dressed, get there, do the work ...and if the extra money you get for that is only like an extra twenty or thirty dollars it’s like, well, why would you do it? (Peer support worker)

While some described life on a pension as “getting by” others openly expressed a measure of contentment with their lifestyle:

....unless I can get a job that allows me to sit on my bum and work I’m going to continue with the disability support pension ’cause I’m doing quite nicely. Once you get the normal pension, plus you get the things like the rental allowances and all that, I’m doing alright. I mean ...I go to [interstate], I get expensive shirts, expensive shorts, expensive pants, I’ve seen the [major sports events]... (Client with schizophrenia)

Some who had not worked for a long time were seen to have adapted to living on the pension and were perceived to be “more than happy not to work”. Others were perceived to have settled into a lifestyle they would not want to change:

I mean you get some of these guys and they’re not going to do anything and why? And the answer some of them will give you, if they’re honest, is, “Well why would I? I get to live with my parents, who cook my meals, who provide me with some spending money. I get to go to the beach every other day, in paradise. I get a car that they loan me” or whatever, however their set-up is...these are the better ones. Why would I change that? I’m happy with this...I drink alcohol and I smoke pot and I’m quite happy, thank you very much. (Psychiatrist)

Others, after careful consideration of their financial situation, did not consider they would be financially better off if they worked. A client with schizophrenia, who had an extensive work history, said: “...because of my *income barriers*, I haven’t set any work-related goals... that does affect our *entitlements to work*...I’m in a no win situation with work, where my income is concerned.” He felt the hours and income he would need

to earn to make working worthwhile would not justify the effort: “It’s just my income barriers that have affected my motivation to do any work, not my condition...bear in mind I have had my illness all my life.” It appears that for people earning low wages, the marginal financial benefits of working would be insufficient to compensate for the loss of the sense of security associated with the disability benefits. Others seemed satisfied with volunteer roles at non-government organisations and did not wish to pursue paid work. A client with schizophrenia said, “I guess at the end of the day I enjoy my life at Clubhouse too much to really be bothered by looking at paid work...that’s really what it boils down to now”.

***Disincentives.*** For those who considered themselves capable of working, social security regulations seemed to have major impacts on work-related decisions. Several respondents expressed concerns that working or increasing their work hours would result in reduction or loss of entitlement to social security payments and benefits. There was a perception that people on DSP who *do* work are penalised. A politician stated: “I think it doesn’t encourage people to get out because, once again, if they do find work they’re penalised...” For those in receipt of a disability support pension, there appeared to be wide-spread fear around the impact of return to work on pension payments. The system of deducting payments from disability support pensioners who commence work was seen as a disincentive to work.

Participants related experiences of disability support pensioners being cautioned against work or study due to concerns about loss of the pension:

“According to [person with schizophrenia], who’s the one who knows about these things, the barriers to him working are that when he asked for support from the

government- he's always wanted to study- but the [social security agency] or whoever it was that he had to go to said, "Don't do it...Don't study. Don't work. You are on a full pension. Any study that you do, any work that you do, you'll have your pension taken off you". (Family member)

It appears that even employment service providers may advise disability support pensioners to restrict their working hours due to concerns that the jobseeker may lose the disability support pension.

Participants stated that some people feel it is not financially worthwhile to work or increase their working hours due to deductions from, or loss of, their pension payment as well as potential loss of entitlements. This was confirmed by an employer who said, "Well we've got a couple of guys that we've offered more work to and they've said no because their payments will stop...if they work too much they lose that".

Some people felt that their financial situation would not improve if they commenced work. For others, the rewards of working were perceived to be minimal and would not justify the extra effort and expenses involved in working:

I told them [social security agency] how much I was earning and then they still deducted money off my disability [pension]. I said, "Well how come you say you can work eight hours a week and yet you still deduct money off your disability?" And they say, "Well you can work eight hours a week", but they don't say anything about how much you can earn. Yeah, like nine dollars an hour which is under the award rate....and I just didn't feel good because I thought well if I got to go out and work and I can just stay at home and do nothing...by the time you've

put fuel in your car and do all that to get to work, you think...I'm not really worried about it... (Client with bipolar disorder)

There was a perception that some disability pensioners might even be worse off if they work, and some participants seemed convinced that in their circumstances this would be the case. A psychologist affirmed, "I mean there are people who think that it costs them more to go to work; they might as well just stay at home on the dole ..."

Concern was expressed that return to work may result in loss of entitlements such as the health care card and rent subsidy. Particular concern was expressed about loss of the health care card, without which the expense of ongoing medication was seen to offset the benefits of any additional earned income. An employment consultant observed, "...the running theme with our clients with mental health is I can't afford to lose my healthcare card..." Several participants commented on the significant costs associated with ongoing psychotropic medication required to maintain the stability of their condition:

I've got a job that's been offered to me right now but if they give me two overnights I'm going to be stretching my thirty hours. I got in a stage they call grandfathered area when I got into the disability...and if I go over this two hours am I going to be jeopardising my medication? That's the worst...that's the thing I can't handle because I don't want to go off of it...that's keeping me stable...It's \$120 for a box that'll last me about four weeks, six weeks. So, you know, the medication is costly. So I'm willing to work as a person in society with bipolar more hours while I'm stable but...I might lose the benefits of that [health care] card... so that's what I'm worried about... (Client with bipolar disorder)

Concerns over loss of the health care card were corroborated by a peer support worker:

...he was worried about losing his health care card because he's on so much medication that without his health care card it's going to cost him an arm and a leg for his medication so he needs that health care card but if he works too many hours or he makes too much money he'll lose that card and then all that money he's making will go on his meds. It's a real balancing act and it's not a balancing act that if you're unwell that you really need to deal with....Where's the benefit? You know, you take away any person's initiative to go to work. (Peer support worker)

... when I was doing two days, I think I was doing sixteen hours a week, and I was earning too much to get a partial health care card and I'm on medication too. I was earning too much, only by something like about twenty dollars a week, and for twenty lousy dollars it was costing me money to go to work...rather than staying on Newstart. (Peer support worker)

There were also concerns expressed about possible delays in re-instating the disability support pension in the event of loss of employment. A community participant also raised the issue of carers losing their carer payment if the person went to work.

***Welfare dependency.*** The disability pension was described by participants as a “safety net”, a “security blanket” and a lifeline.” A peer consultant said, “...the pension's like a real safety net. It's a security blanket and it's easier [than working]” It appears that for many people living with these fluctuating conditions there is significant fear about reduction of payments or loss of entitlements associated with return to work. People were perceived to be reluctant to give up the disability support pension due to lack of

confidence, fear of relapse if they increase their hours and concerns about perceived difficulties they might experience including delays involved in re-applying for the payment if their job does not work out. A psychologist commented, "...for a lot, who feel vulnerable, that payment is a lifeline and I think the fear of losing that security stops them even looking." The availability of disability payments which do not require job-seeking was seen as reinforcing people's belief in their incapacity and constituting a disincentive to work.

Fear of losing the disability payment prevented some customers from even seeking work and resulted in others refusing opportunities to increase their work hours. It seemed that the major factor in reluctance to give up the DSP was a lack of self-confidence in their ability to sustain the work.

It was also suggested that some people may become psychologically dependent on the disability pension:

...just because you've got bipolar or you've got schizophrenia, you get put on disability [pension] which is, it's sort of harder for the patient to start thinking back to working for themselves. It's actually counter-therapeutic because you've got a person who's had a big illness and you actually sort of rob them of the opportunity of socialising and working etc. etc." (Psychiatrist)

Long-term unemployment was seen to result in adaptation to a welfare-dependent life-style and work de-conditioning:

...the old "use it or lose it" sort of idiom, that's basically what I was in. I don't really want to work, you know, so what's the point? I've been getting by without working so why go for anything? (Peer support worker)



It was suggested that some people who have become accustomed to living on a small income for a long time may prefer to enjoy the benefits of not working such as freedom, lack of stress and challenges, and avoiding some of the financial and emotional costs of working.

***Social security processes.*** One participant considered the system focuses on proving inability to work rather than directing more attention and funding to enabling people with a mental health condition to find a suitable niche in society. The obligations around reporting income to [social security agency] and time spent waiting on the phone for this purpose were considered deterrents. Reporting requirements associated with working were viewed as onerous, particularly having to wait in phone queues. There was a perception that monitoring and reporting income was an onerous task and that people with psychiatric disabilities were expected to endure long waiting times in the phone queue in order to report their earnings. A participant commented, “The hassle, if you earn a bit too much, you’ve got to ring up and it’s taken off...it just, all that just drives her [friend] mad.” It was also felt that calculating the financial implications of work was a complicated process. Another participant identified a service gap in relation to support with job retention:

... I actually went to [social security agency] and said to them, “Look, I’m in fear of losing my job because I’m unwell” and they stated to me, they said that you can go back onto disability with no problems about that, but not once was it mentioned to me that I could get assistance with my job through Job in Jeopardy, which is part of the disability employment network. (Client with schizoaffective disorder)

A psychologist expressed the view that cancellation of DSP and being forced to undertake compulsory job-seeking requirements would have the potential to de-stabilise the condition. Concern was also expressed about additional burden of forms to be completed and delays involved in re-instating the disability pension in the event that work is unsustainable and is terminated. Administrative processes and perceived delays involved in re-applying for DSP if the job terminates were perceived to be a deterrent to work for some people.

**Assessment issues.** One participant pointed out that a limitation of the current system of job capacity assessment is that it does not take into account the important role of contextual factors in determining a person's work capacity, and that the nature and extent of support afforded by managers and co-workers in the workplace can significantly increase or reduce a person's work capacity. Multiple factors were perceived to impact on the accuracy of current employment-related assessments. These are listed in Appendix K.

**Housing.** Issues relating to homelessness and lack of stable accommodation were also identified:

... the government not supporting financially with just, things like a computer and a house, somewhere to live to be able to go to work every day. A lot of the people that my brother and I know, don't have homes. They live in other peoples' homes and they just go from home to home to home until they get kicked out ...and then they go, "I'm really hungry, I'm really off the wall" and then they put themselves back in hospital for six months. So that kind of lifestyle, with no stability, is not going to be conducive for anyone, let alone struggling with schizophrenia or bipolar, to have a regular job. (Family member)

**Public transport infrastructure.** Inadequate public transport facilities were cited as another barrier, particularly for those living in more affordable areas:

I was doing a job last year doing [trade] and I had to be at work at 4:30 in the morning and I had to ride my bike from the other side of the xxx down to xxx and I did that for a little bit and then I just threw in the job... (Client with bipolar disorder)

**Fragmentation of services.** Fragmentation of services was seen to constitute a significant barrier to employment. There were references pertaining to gaps and disconnection between disparate services provided to people living with a psychotic condition by community, state and federal bodies. Segregated mental health and drug and alcohol services which do not communicate with each other were seen to pose a significant barrier for people with dual diagnosis accessing services:

I've heard of many, many cases where someone goes to the mental health unit and they say "Ah look you've got an alcohol, drugs issue you need to go over to [drug and alcohol unit]." They get over to [drug and alcohol unit] and they say "Ah no you've got a mental health issue...you need to go back" and they just keep getting [turned away]...and in the end they give up, of course. (Politician)

Integration and collaboration between sectors concerned with employment was noted as sub-optimal. Health professionals from within the public and private sector stated there was a lack of time and funding to devote to discussions around employment. One clinician pointed out that health personnel have over the years handed over their role in employment to employment services. Communication gaps were identified within treatment services and between health services and employment services. There appeared

to be some role confusion among clinicians as to their own role and that of the employment agency in exploring career goals and direction. Health providers commented on the lack of feedback from employment providers on employment outcomes. One employment consultant reported communication barriers with the public mental health system:

Case managers are pretty good, however, their caseloads are pretty horrible too and their burn-out rates are pretty high so you may work with that person with their case manager for three or four months, [then] the case manager leaves. You've got this continual rollover of staff and relationships so there really isn't enough time to build that really good rapport that supports the person from both sides. (Employment consultant)

Ineffective communication and information-sharing between stakeholders involved in employment was perceived to constitute a significant barrier. There was also evidence of role confusion and less than optimal synergy and information-sharing among clinicians, [social security] staff and employment service providers in preparing a client for work:

I was working with a lady on some vocational goals and she went to [social security agency] and she was quite keen to get a job and then someone suggested the DSP and said she could get more money on that and I was really disheartened that someone was pushing that on a young, capable person that really could have been in meaningful employment and have career goals. It reinforces that they shouldn't be doing things because of their symptoms, rather than they *should* be doing things *in spite of* their symptoms... (Health professional)

Employment service providers also identified a disconnection between the education system and employment providers in regards to at-risk students.

**Ethical concerns.** Health professionals expressed concerns about ethical issues in relation to employment, specifically possible political motives around efforts to improve employment outcomes. They felt that the decision whether to work should be left to the individual rather than imposed from without. There were concerns about the possible destabilising effect of job seeking on people with major mental health conditions if pressure was exerted on them to work. There was also concern expressed about making people feel devalued if they are without a job. It was evident from talking to employment service providers there were numerous "good news stories" of positive employment outcomes, although it seems clinicians are not typically informed of these outcomes. The individualistic, laissez- faire approach to work adopted by some health professionals was perceived by other participants as a failure to encourage people to return to work.

**Education policy.** There was reference to lack of public education when de-institutionalisation occurred. Very few participants acknowledged receiving any form of education about mental health issues at school. Several participants, including teachers, said that they had received no information regarding mental health conditions during their formal education, and that knowledge in this area had been derived mainly from television and movies. Many participants pointed to the powerful role of the media in influencing their perceptions of mental health conditions, usually in a negative fashion, through sensational reports around violence.

There was evidence mental health remains a taboo subject in schools. A university student disclosed, "I went to a public school and it was just never talked about.

They would only talk about something that directly affected us and our performance like the bullying”. Another university student concurred, “I guess when I was finishing school like it was a massive stigma....I think people just avoided it unless one of their friends was affected.” A school teacher remarked:

...there’s a counselling service at school like a guidance officer that you can go and talk to but that’s kind of...I think there’s a bit of a stigma....it’s not cool to go to her and talk about your issues....you’re [considered] weird if you need to go and talk to somebody. (School teacher)

Those who did receive education at school felt the educational approach was ineffective:

So I think when they talk about it in a big meeting it’s like about something that never really happens. “We’re just warning you guys. You’re probably not going to need it”. Like maths, you think when am I going to need this and you don’t pay attention. So that’s a shame when they do try and do things, they do the wrong things. (University student)

One respondent felt the message he had received at school was neutralised by conflicting media coverage. Another respondent indicated that funding available to schools for educational activities during mental health week activities was inadequate. A student considered her education had not prepared her to respond appropriately to people living with schizophrenia and bipolar disorder:

I’ve never through all of school been taught about mental illness in any way. Genetic diseases were covered in biology but it was never mentioned. Mental illness was just never mentioned and it was just sort of swept under the carpet which it isn’t right because you come out the other end and don’t know how to act

around people who have it and you don't know whether to be over-caring, over-sympathetic or avoid it and neither is beneficial. It was never taught...

(University student)

A number of teachers who participated in the study stated they had not received any training on mental health conditions during their schooling or tertiary education studies. There does not appear to be any training of school teachers in schizophrenia or bipolar disorder, despite the fact they are likely to come across parents or students with these conditions. An educator who was asked when he had first learned about schizophrenia and bipolar disorder said:

... I'd heard the terms used but I didn't really understand what they meant and hadn't come across any cases or met anyone. But then, at a professional level, as a principal later in my forties, came across my first case of a parent who was bipolar and somebody had to explain to me exactly what that meant...

(University lecturer)

Teachers as well as parents were seen as potential barriers to integration of mental health literacy into the school curriculum. A former school teacher spoke of efforts to introduce a mental health awareness program into school twenty years ago and how it took eighteen months to convince parents "[we] weren't doing something bad." When asked about reactions expected from teachers to introduction of mental health awareness into the school curriculum, one educator considered there could be those who feel the curriculum should focus on reading, writing and literacy, while strongly held prejudices would be another possible barrier.

A lack of support was identified for children who do not adapt to school or have special needs and seem to become lost in the transition from school to work. Others may drop out of school and may develop drug and mental health problems. Experience of stigmatization at school may affect willingness to expose oneself to further stigma in the workplace. An employment consultant attested to a lack of young people with these disorders on her caseload.

In relation to tertiary education and training policy, one respondent had accessed disability specific study assistance at university, however explained that the type of support offered did not meet his study need and that he had eventually sought assistance from a family friend. Another respondent said that some people living with psychosis who undertake study may experience difficulty making the transition from study to employment due to lack of self-belief. No employers in the study acknowledged receiving any form of tertiary education or training to support people with mental health conditions, although one respondent mentioned he had attended training in managing people with physical disabilities. A psychologist pointed out that university courses in psychology do not teach evidence-based practice in relation to employment support for people living with schizophrenia and bipolar disorder.

### **Ideological Factors**

Ideology contains references to influences that shape and perpetuate public consciousness regarding employability of people with mental health conditions. It captures references to historical precedents, the role of language, shared beliefs and media images which serve to perpetuate the status quo.



**Historical antecedents.** Several respondents recalled the historical precedent of exclusion of people living with psychotic conditions from society and there was general awareness of the ongoing stigma associated with psychiatric diagnosis and treatment. There was a sense of despair and hopelessness among many of those participants most affected, that “nothing has changed” over the years as well as low expectations regarding the expected rate of real change in the future. There was also scepticism that political rhetoric has failed to deliver material changes.

**Work-related myths.** Commonly held myths concerning the employability of people with severe mental health conditions became apparent in this study. These myths appear to serve a dual purpose of both explaining and justifying the low employment rate of people with psychotic conditions. The main myths were that people living with a psychotic disorder can’t work or don’t want to work.

***Can’t work.*** The most frequently referenced myth was that people living with psychosis can’t work. This idea was generally refuted by client participants. A participant with bipolar disorder in full-time employment said: “I’m still capable of working. You know there might be something wrong with my mind but there’s nothing wrong with my body so I’m still capable of working.” Likewise a client with schizophrenia said, “...my condition definitely hasn’t been affected my [ability to work], it’s just my income barriers that have affected my motivation to do any work, not my condition”.

Another respondent said:

I know people who hear voices or receive messages in their heads and I know that they’re capable of working and for some reason they’ve been put on the

scrapheaps for the rest of their lives. It's an extremely serious problem. (Client with schizophrenia)

There was also evidence that people living with psychosis are considered less competent or only capable of sheltered employment. Contrarily, there were several participants in the sample with lived experience of a psychotic condition effectively working in open, unsupported employment. A number of other stakeholders also made reference to positive employment outcomes. An employment consultant attested, "...with job seekers with schizophrenia or bipolar, when the condition is stable they can be the best workers..." See also page 197.

***Too stressful.*** There was also evidence of concerns that working may be too stressful for people living with a psychotic condition. Conversely, several participants described heightened stress during periods of unemployment and considered their mental health to be better during periods of employment. It was also pointed out that work-related stress can be alleviated by appropriate support and good management practices. This is how one participant described her experience of unemployment compared with employment:

...depressed, suicidal, can't function, don't want to go outside, get agoraphobic, won't go see people, don't like to be around people, hibernate in the house with my parents...hibernate in the house with my animals, get paranoid, think everybody's just out to get me...When I'm in work I'm on top of the world. I have a lot going for me. I can see a future. I can see myself having children. I can see myself going overseas. I can see myself doing a lot of things. If I'm

unemployed I don't see anything...I don't see any kind of a future or anything for myself...nothing...may as well not even be alive. (Client with bipolar disorder)

Another respondent said of unemployment: "I found that the more that I was out of work the more that I lost a sense of self..."

***Must be symptom-free.*** Some participants felt that active psychotic symptoms would preclude work. Others felt that, due to the nature of psychotic conditions, some people may never be symptom-free and that it is not uncommon for people with a range of medical conditions to work despite ongoing symptoms:

...it's not an uncommon thing at all for people to be working and managing conditions. That's a very normal thing...whether it be a mental condition or physical condition or genetic condition....and if people are waiting to be clear and free of symptoms they'll only go to work and find that Jo Bloggs is coming to work with a cold, and sniffing everywhere and miserable, or so and so's been out too late night before and they're tired. And you don't have to be perfect to be working. (Psychologist)

It was also pointed out by health professionals as well as clients that work can serve as a helpful distraction from troublesome symptoms.

***De-stigmatisation must occur first.*** One participant believed education of the community is a necessary precondition for people successfully entering the workforce. This belief was contested by other participants who felt increasing exposure of the community to people living with psychosis through employment would in itself be a powerful means of de-stigmatising these conditions. Some participants affirmed that

having had the opportunity to work alongside a person with a psychotic condition had helped to normalise it.

***Don't want to work.*** Another common myth was that people living with a psychosis do not really want to work. This notion is contrary to the views of a number of participants. A client with bipolar disorder declared, "I want to work, I desire to work, it's my passion and purpose to work". Another client with bipolar disorder remarked, "I like to work. I've always worked so it's a big part of my life and who I am. I couldn't imagine not working".

Some community participants felt people with psychosis are not really interested in achieving high level positions, and that just getting a job would be good enough, even if it involved unskilled work. This was contrary to the views of some participants with lived experience who said they were not interested and would refuse to perform work that was inconsistent with their interests, level of qualifications, skills and experience.

**Media influence.** It was clear most respondents were heavily reliant on the media, and in particular television, as their prime source of information about mental health conditions. People lacking direct experience were seen to be heavily influenced by the media. Some respondents reported film and television as their earliest or sole source of information on these disorders. A politician commented: "...there are so many people who have not dealt with someone with a [mental health condition]...particularly if we're talking schizophrenia or bipolar. Many people have not dealt with those issues so they read the media".

Several participants expressed the view that "the media has a lot to answer for":

...the media can totally change a person's perception of what's possible...and they just wield such a big stick and I know they like to say that they're fair and they're honourable...but sometimes I just think they can do more damage than they realise." (Politician)

It was suggested the media tend to selectively report negative incidents involving people with mental illness and fail to report on healthy, happy people who are coping with their condition. Participants reported a predominance of negative messages, especially in relation to schizophrenia, with reporting characterised by exaggeration, paucity of positive stories, unbalanced and sensationalised reporting, focus on violence, risk, unpredictability and anti-social behaviour, as well as a lack of education on the impacts of drugs on mental health. It was considered that the media has a powerful influence in stereotyping of people with these conditions and perpetuating misconceptions. Several participants also felt that the media was largely accountable for perpetuating the negative image of conditions such as schizophrenia and bipolar disorder, and that the general public were also frightened of what they hear in the media. Participants perceived that media portrayals of violent crimes appear to play an important role in reinforcing negative stereotypes of violence. Several respondents reported examples of media reports highlighting violent crimes committed by people with mental illness. People living with these conditions were also perceived to be affected by media portrayal. It was felt that positive use of media engenders hope while negative stories shape perceptions of dangerousness and reinforce stigma, which in turn impacts on self-esteem, motivation and hope for recovery.

There were several references to movies featuring schizophrenia or bipolar disorder, with reference made to images from “Rain Man” and “One Flew over the Cuckoo’s Nest” and, on a more hopeful note, “Beautiful Mind” and “Mr Jones”. In regards to television, participants perceived a lack of positive stories on the news or prime time television programs:

I think the biggest issue is the news. They don’t show you loving stories about people helping people...so how can you say that community people are going to help unless they are aware and know they need to change? (Community member)

Respondents also referred to the role of the press in shaping public attitudes and perceptions. The press was mentioned in the context of irresponsible reporting, including negative reporting in newspapers and magazine articles. An employment consultant asked, “When was the last time you heard a good feeling story about a person with a mental illness on the news?” to which another responded “Rosy stories don’t sell papers”. Yet another employment consultant observed, “You don’t see a Current Affair saying ‘look this guy’s worked for four years he’s now the manager of a business but gee he takes anti-psychotics every day of the week you know’”. High quality television documentaries of people with lived experience of schizophrenia or bipolar disorder were acknowledged as “great stuff”, although respondents also noted that these tended to be scheduled during off-peak viewing times.

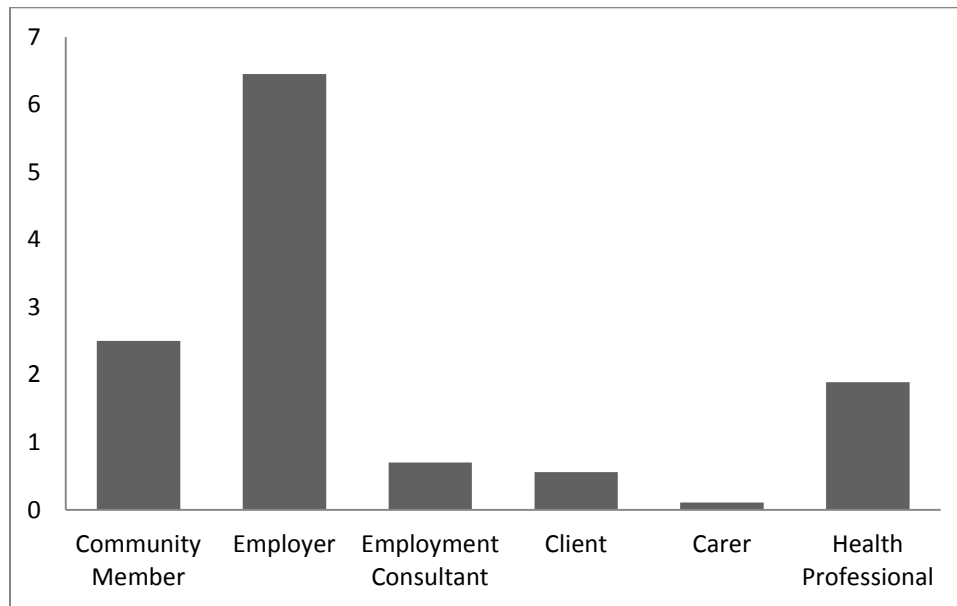
**Linguistic issues.** Language was identified as a factor influencing public perceptions concerning employment potential. A family member commented, “...language is a sticky and tricky thing”. Commonly used terms such as “disability” were

seen to be disempowering and antithetical to the notion of work. A psychologist stated “...the fact that it’s called a disability benefit, you can read into that if I’m eligible for that benefit I must be disabled...therefore that’s where I am....and I can’t move beyond that.” Several participants commented on the frightening nature of some psychiatric terms such as *manic depression* and *schizophrenia*. A client participant also referred to the limitations of language and the difficulty he experienced finding appropriate language to explain his subjective experience to an employer.

**Social priorities and values.** Participants showed awareness that current social behaviour and practices in relation to people living with psychotic experiences are discrepant with some commonly espoused values. One participant observed “Australians are pretty happy to jump on bandwagons as a rule and there’s a lot of stigma associated with a pronounced mental illness.” Several participants questioned and criticised social attitudes and behaviours towards workers with a psychotic condition, and identified a discrepancy with values generally upheld in Australian society such as egalitarianism and inclusivity. The exclusion of people with major mental health conditions from socially valued roles and opportunities was symbolised by a psychologist who observed: “....we’re just side-lining people with a mental illness and condemning them to life as a pot plant.” In particular, the persistence of sheltered workshops and supported wage scheme was attributed to a lack of social priority and will to make adjustments that would enable people to work in mainstream employment at award wages. A number of community participants felt it would be too hard and too costly to change the status quo.

## Legal Issues

The most common legal concerns discussed were privacy issues and concerns over the application of anti-discrimination law and unfair dismissal. Figure 39 shows the frequency of references to legal issues according to stakeholder group.



*Figure 39.* Average number of participant references to legal issues according to stakeholder group.

Employers were particularly concerned about legal issues and especially the implications of knowingly or unknowingly employing persons with mental health conditions. The majority of references to legal issues centred on attempts to clarify employers' rights and responsibilities in relation to employment of people with schizophrenia or bipolar disorder. One employer described this area as a "legal minefield". Employers appeared to be keenly aware of occupational health and safety legislation and felt the onerous nature of this legislation would be a deterrent to knowingly recruiting a person with a mental health condition in certain types of work.

One employer, highlighting a paradox inherent in anti-discrimination laws, stated



company law requires company directors to discriminate in favour of share-holders, which, in turn, requires risk management in staff recruitment. Current legal processes were seen to be costly, onerous and inconvenient, hence a deterrent to recruitment. One employer pointed out that some staff, terminated for legal reasons, attempt to obtain “piss off money” in the knowledge that companies find attendance at the tribunal hearings onerous and inconvenient.

Client participants, on the other hand, felt that existing laws do not always achieve the desired result:

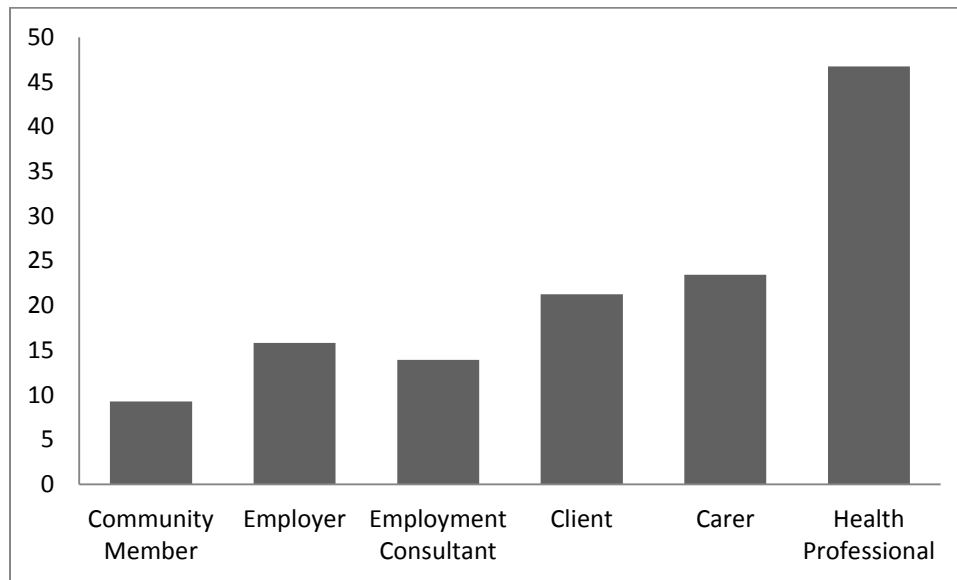
If you have a mental illness and you’re working, the law states that you have to be given the opportunity to recover from a mental illness and retain your employment but that’s what the law says. What happens in reality is often very different to that. (Client)

Employment service providers considered privacy law often constituted a barrier to the exchange of relevant information between agencies. However, other participants felt that processes were in place to allow for the exchange of information between agencies. One participant considered that in paying too much attention to privacy issues, duty of care is sometimes compromised.

### **Summary of Systemic Barriers**

The most frequently referenced systemic barriers were government policy (669 references); ideological factors (151 references); economic imperatives (140 references); and legal issues (96 references). Government policy barriers included references to government policy across several areas notably mental health services (224 references); employment policy (190 references); and social security policy (140 references). Labour

conditions (129 references) were identified as a major topic under economic imperatives. The total number of coding references to systemic factors according to stakeholder group is shown in Figure 40 below.

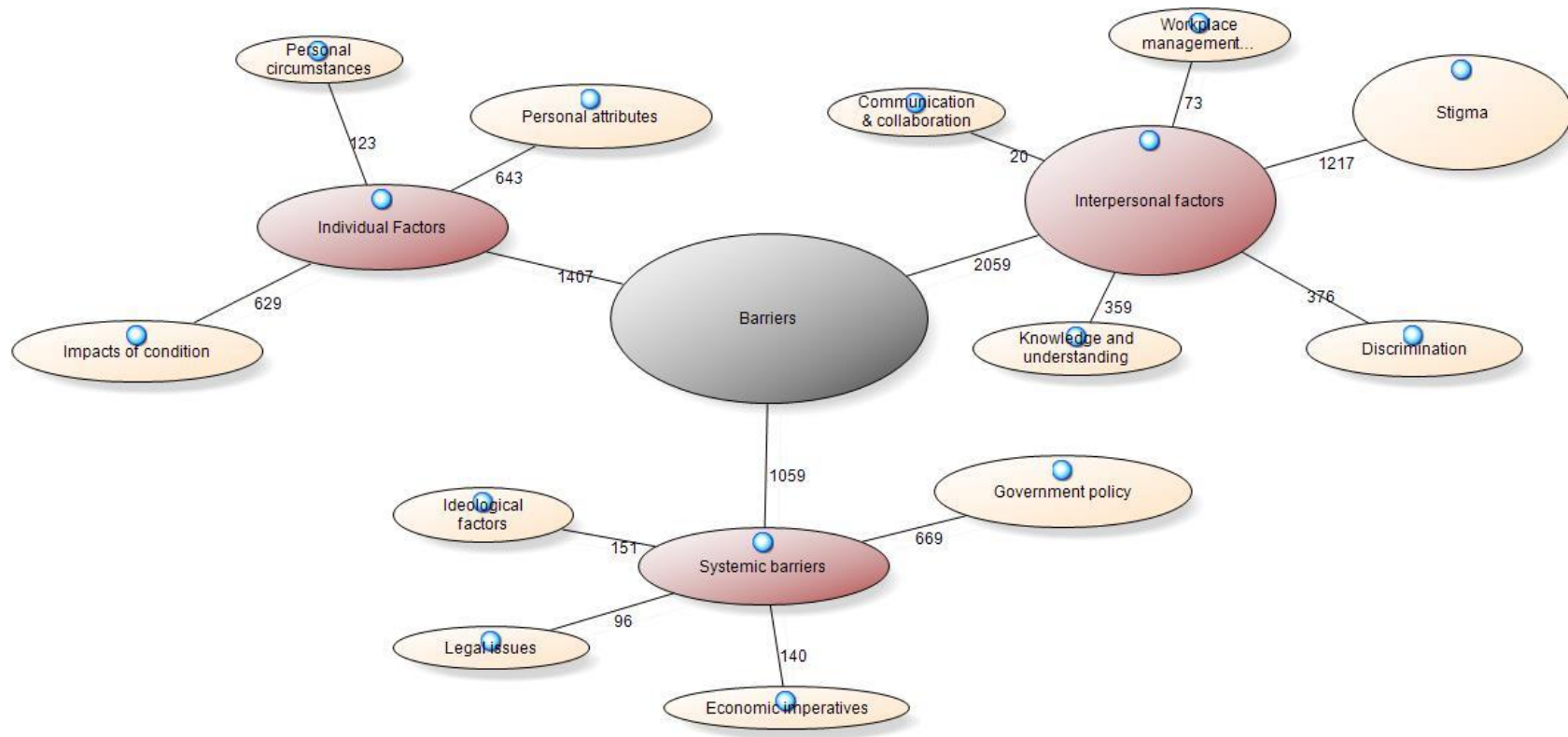


*Figure 40.* Number of coding references to systemic factors according to stakeholder group.

### **Overall Summary of Barriers**

A summary of the main barriers to employment is shown in Figure 41.

As can be seen in this figure, the most heavily coded barriers to employment overall were interpersonal factors, notably stigma. Figure 42 is a schematic diagram of the barriers to employment



*Figure 41.* Comprehensive model of employment barriers showing coding density of nodes. The numbers entered adjacent to connector lines represent the coding density (number of references) by all participants to each of the main barrier nodes.

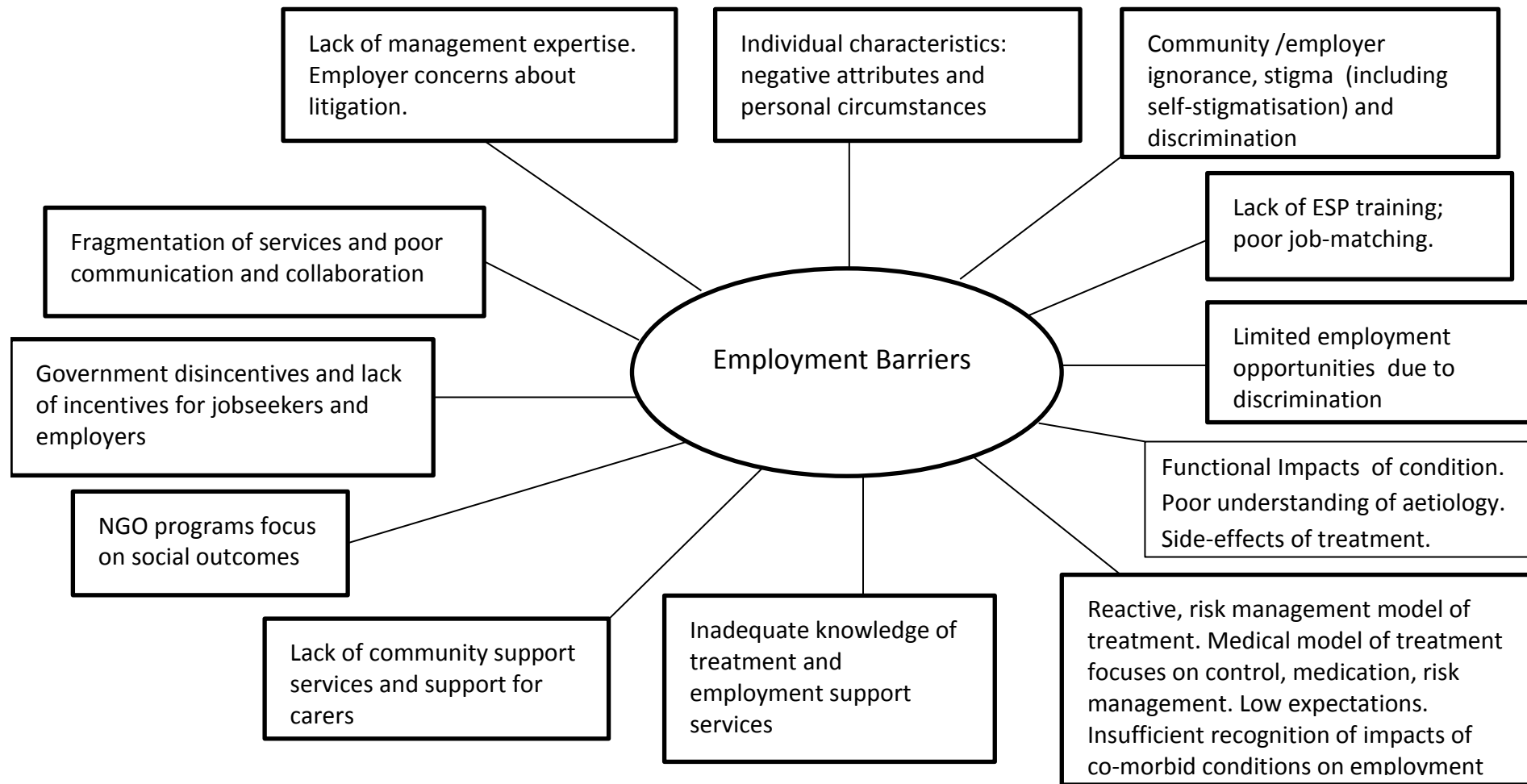
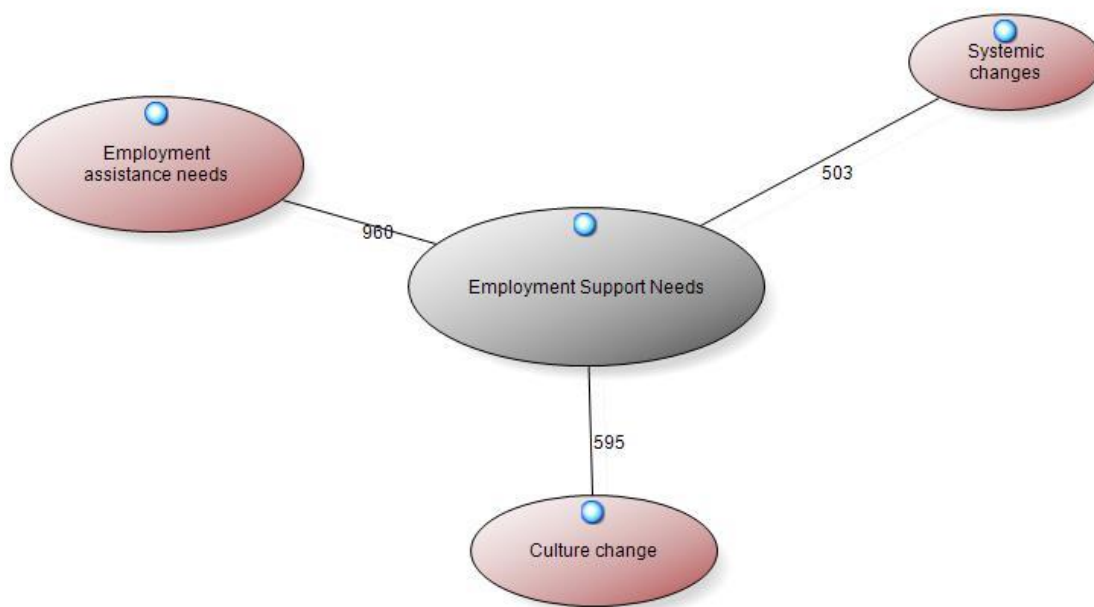


Figure 42. Schematic Diagram Showing Barriers to Employment.

### Overview of Employment Support Needs

This section reports on the aggregated results for employment support needs across the combined sample representing all stakeholder groups (N=137). Only support needs explicitly identified by participants have been reported in this section. The most frequently referenced employment support needs for people living with psychosis could be broadly categorised as culture change, employment assistance and systemic changes. Figure 43 below shows the frequency of coding references for all participants in the study against each of these support needs.



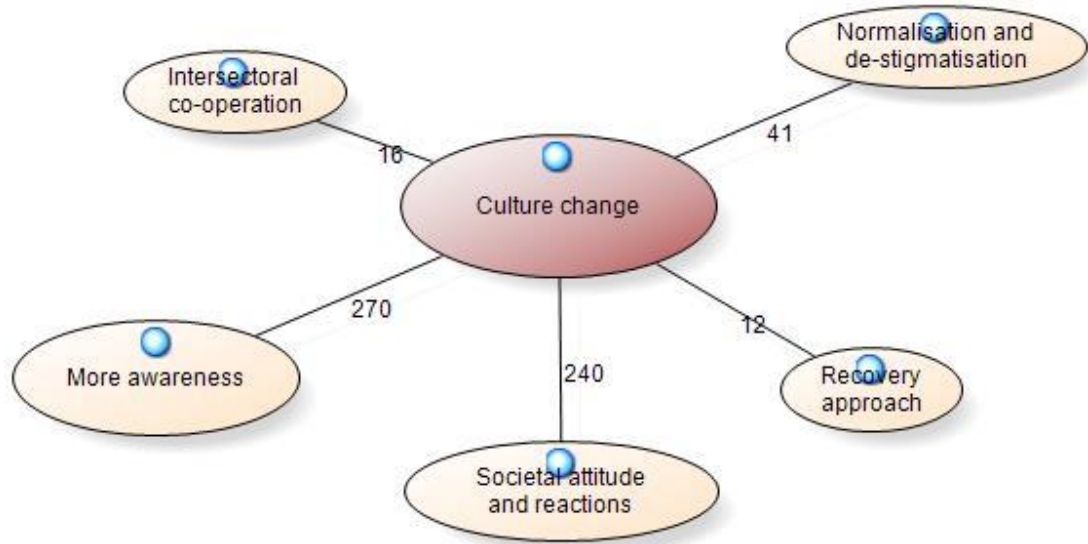
*Figure 43.* Overview of employment support needs.

As can be seen from the above figure, employment assistance was the most commonly cited support need identified in this study.

The next three chapters (Chapters 11-13) will provide detailed discussion of the findings in relation to each of the three main employment support needs identified by participants: culture change, employment assistance and systemic changes. Each chapter will describe the contents of the most heavily coded employment support needs nodes. Findings will be illustrated using visualisations of the data and narratives provided by participants. Some differences between stakeholder groups in their perception of employment support needs will also be presented. A comprehensive model of the employment support needs results is shown in Figure 54.

## Chapter 11: Culture Change

Culture change incorporates references to the need for more awareness and change in the attitude and behaviour of society towards people living with psychosis. As shown in Figure 44 below, the most frequently referenced culture change needs were for more awareness; change in societal attitudes and reactions; and normalisation and destigmatisation.



*Figure 44.* Summary model of culture change needs. The numbers entered adjacent to connector lines represent the number participant references, or coding density, for each of the main barrier nodes.

A more detailed analysis of culture change as an employment support need is provided in Figure 45. This chapter will focus on description of the contents of the most heavily populated nodes.

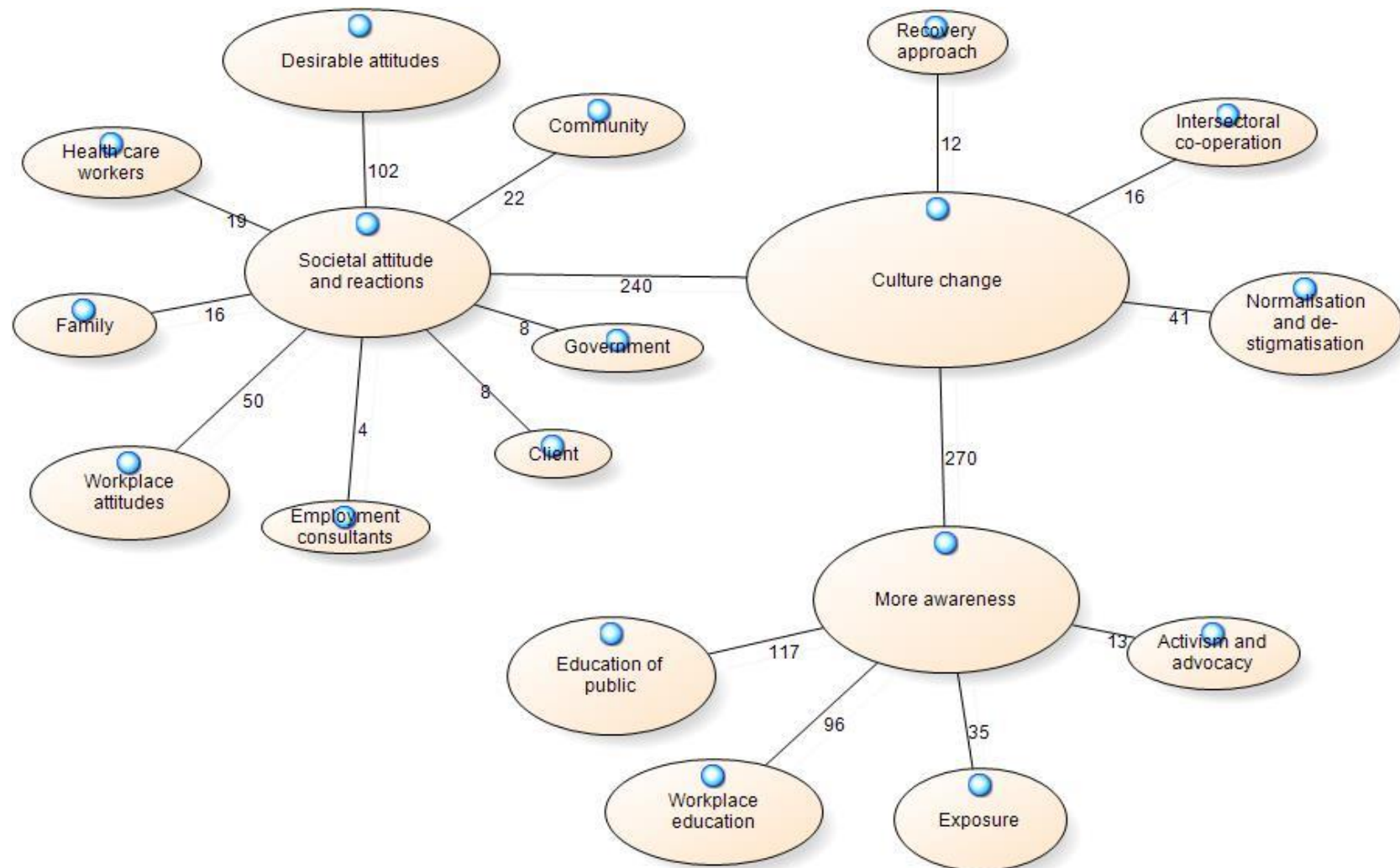


Figure 45. Second order analysis of culture change needs.



Participants referred to the need for "culture change" in regard to attitudes towards people living with psychosis. The usage of this term implied a shift in attitude away from stigma and discrimination towards valuing and inclusiveness:

I just think they need to stop discriminating against people and it's really unfair the way they're treating people and really shutting them out from opportunities to earn money, make friends, have some sort of status in society.... (Peer support worker)

Respondents voiced a need for more awareness and understanding as well as change in the attitude and behaviour of society towards people living with a mental health condition. In terms of culture change, there was a call to reduce stigma and to educate the community including employers.

### **More Awareness**

There was strong consensus among participants regarding the need for more awareness among the general public and in the workplace. It was suggested this would be achieved through public education, workplace education and more exposure of the public to the experience of people living with schizophrenia or bipolar disorder.

**Education of the public.** A major theme that emerged was the need for more community education and understanding regarding psychotic conditions. An educator stated, "once the unknown is exposed and the light shone in a very transparent manner, I think some of those barriers can be broken down." A client with bipolar disorder said: "...as opposed to the general public understanding, or knowing or accepting, I think, you know, yeah, that would be good one day...."

Participants talked about need for a “mind change”, although some predicted this will never happen. Suggestions included funding to improve community awareness and understanding of bipolar disorder and schizophrenia. A need was expressed for population level education so people know what these conditions are, how to recognise them and to overcome ignorance, prejudice, discriminatory behaviour and fear. The need was expressed to de-stigmatise these conditions in the community and develop more awareness and acceptance. Participants identified a need to educate the public in order to dispel commonly held myths and stereotypes and reduce fear of employing people. Knowledge that there are different levels or degrees of these conditions seemed to be important for community members and employers. Responses indicated a need to increase public knowledge and awareness regarding the incidence and nature of psychotic disorders, and that they are manageable conditions. Participants expressed a need for better understanding of the subjective experiences of people living with psychosis, including what it’s like to be different, the stigma people with these disorders suffer and the need to overcome it. Participants suggested that public education should use high profile figures and positive role models. It was considered this would help to overcome judgemental attitudes and a tendency to “write people off”. There was also wide-spread endorsement of the need for more education on mental health in schools.

There was reference to positive use of radio, television, film and press and the role it can play in building hope and eliciting empathy. Television was seen to be the quickest and easiest way to influence public attitudes, especially among children. It was also suggested television programs, rather than portraying people with schizophrenia or

bipolar disorder as sick, should integrate them as capable people who can work and live normal lives. It was suggested stories about prominent figures and sporting stars affected by these conditions could assist to break down social stigma. Extensive public recognition of success stories, including those of average people moving towards recovery, was seen as a means to diminish stigma. It was however recognised that stigma itself could make it very difficult to share such stories in the public arena.

Participants suggested that positive media images and stories that elicit empathy and inspire hope were needed to balance the negative images usually portrayed. Although costly, anti-discrimination adverts on television and posters were also seen as a powerful means to stimulate discussion, normalisation and acceptance of these conditions. A need was identified to encourage and reward reporters, journalists and media people for responsible reporting.

More publicity was suggested, such as pamphlets and other user-friendly resources in doctors' offices and other public places, to increase public awareness of the availability of support services including employment support services.

### **Workplace education.**

***Employer education and training.*** There was general agreement that people who want to work need an understanding and informed employer. A medical specialist commented, "...you need an understanding employer to cope with this and you need somebody who's a bit more informed about it..." Participants across all stakeholder groups expressed a need for more awareness and understanding among employers.

I think the [Non-government organisation] and the government should really be taking responsibility to educate employers that mental illness isn't a dangerous or retarded type of thing and people with mental illness are capable, because at the moment there's really no education given to employers. (Client with schizophrenia)

...there's a lot of people assuming they are of low intelligence but they're not.

They can be people with high intelligence and quite often are and I think it's education and recognising that they've got something to offer, and being willing to accept that. (Employer)

Specifically, it was felt education of employers would need to overcome fear of the unknown, eradicate misconceptions, and teach skills on how to manage the conditions in the workplace. Participants considered that employers need awareness of the nature, impacts and functional limitations associated with psychotic conditions, and the ability to recognise, monitor and take steps to manage unusual behaviour. The need was expressed for employers to understand and accept the fluctuating nature of these conditions:

Just knowing that maybe one day it mightn't be as good as the next day. One day for me can be harder than the next day for some reason. You go home, you have a rest, you have a sleep and the next morning you wake up and you're feeling good again." (Client with bipolar disorder)

The importance of maintaining medication and willingness to work around the condition to accommodate periods of unwellness were other aspects discussed.

It was suggested that employers should also be informed of the benefits of employing people with these conditions:

... but if you understand that the illness can be controlled, the person would be a terrifically willing worker because they can't just jump from job to job, you know. They're going to stick with it and do a good job. You know you can have a really, really...asset, you know, a real good asset. (Employer)

The perspective and value that people can add in the workforce was captured in this response of a participant with lived experience:

I think you do have an added sympathy for people who are suffering...you're more compassionate I think because you've been through a difficulty yourself and you understand more about what people are going through... (Client with bipolar disorder)

A social worker observed the need to recognise the positive attributes that people living with psychosis bring to society, saying "there's some wonderfully fully creative people out there."

An employment consultant wished employers could develop insight into how workers with mental health conditions might fit into the workplace and understanding of appropriate workplace adjustments to make them feel comfortable:

If they walked up with a gammy leg everyone would go 'Ah you've got a gammy leg? Ah well that won't alter the fact that you can do the job.' They would understand immediately where this person fitted into the parameters of the job and I wish that people would be able to do that, have that insight to know that this

person could fit and this is how they would fit and this is what we would have to do around them. (Employment consultant)

A need was also expressed to inform employers of their legal responsibilities and increase awareness of inequitable and illegal employment practices. There was a consensus that anti-discrimination legislation already exists and that, rather than more legislation, education is the key to overcoming stigma and discrimination. Education was seen to include knowing what to expect as an employer, knowing the risks, likely symptoms, and events that may occur in the short, medium and longer term. Education was also viewed as a means to alleviate employer fear of a staff member committing acts of aggression, by knowing how to defuse situations, cope with and manage any untoward incidents that may arise in the workplace. It was suggested that education should also equip employers with skills to manage the person in the workplace so they can mitigate against the risks and be aware of necessary accommodations, work capacity issues and stressors to avoid. A politician said, "...if a situation was to develop... it would only be fair that they knew what to do or how to handle it..." Participants felt that by educating employers in this way, they would be more willing to employ people with these conditions and facilitate their return to work following periods of unwellness:

I mean as soon as you talk about problems with staff you're describing ninety nine percent of the workforce. I mean everyone's got issues and things they need to deal with. It's just having the tools and skills and the personnel and the funding maybe to manage the issues...if you know what to expect, then that's a barrier that's going to be overcome... (Community member)

A community member said, "...if you train an employee or an employer...let's say for example how to deal with the situation, people would be more willing to hire them."

Another community member supported this, saying:

...educate them maybe in little simple entry level psychology. Like management ways to deal with if someone has a flip-out and wants to kill everybody with a plastic knife, you know, what do you do? If they teach people then that removes a barrier. (Community member)

The fear expressed in the above quote is further discussed in the section on stigma (see page 159). It was also suggested that knowing management and co-workers understand and accept these conditions would make clients feel less fearful of entering the workforce, more comfortable about remaining in the workforce and may reduce the likelihood of workplace episodes.

Community members and employment consultants suggested delivery of education to employers could take in the form of informal one-on-one education by an employment consultant or case worker. It was pointed out, however, that some people job-seek independently and may not disclose their condition to an employer and even if they do, not all employees living with psychosis have a case worker. The government was seen to have responsibility for provision of an education program for employers or their staff. A community member suggested the government arrange seminars for employers where the risks and advantages of employing people with disabilities are discussed. An employer participant suggested this could best be achieved through

organising workshops for employers, led by other employers with relevant experience employing people living with a psychotic condition:

I think as employers we need more information. We need to talk to people that have done what we've done...just more education through our own industries, and the biggest thing is talking to people who have been there and done it because you can have people from government organisations or anywhere saying these people can work okay but unless you've actually experienced it... (Employer)

One employer disclosed that his only source of information was a conference presentation by a person with bipolar disorder, which appeared to have made a positive impression on him. Online training was also proposed:

I think that every employer should have like a module understanding mental health and the workplace 'cause even if you're not diagnosed with it you can have people in the workplace that are suffering from bipolar. That's what I would like to see and I think that is what has to change, the education and the understanding or I can't see any other way. (Employment consultant)

There was support from community members and employer participants for integration of mental health first aid into general first aid courses required in industry. There was also endorsement of the suggestion mental health awareness training should be an essential part of all human resource and management training courses. It was perceived that training staff at management level would influence all levels within the organisation. One participant highlighted the need to equip employers to meet the needs of a diverse workforce:



You may be the last one in a chain of bad managers who, you know, someone is trying to live a productive life. You may be dealing with someone who's had good work experiences and is wanting to continue in them, but you are going to be confronted by people who have physical disabilities, mental disabilities, personality issues... (Academic lawyer)

This respondent suggested the focus of training should not be on avoiding bad management practices such as bullying, but rather on promoting good mental health and cultivating good management practices essentially because people respond better to good management. It was suggested that while smaller companies may not consider this type of training a strategic priority, larger firms may be open to enhancing their corporate image:

...larger corporations do want to be seen as being part of the community, as helping the community and so on, so I'd see the education there would start even as high as board level because you've got to get the head on side before the rest will follow, quite frankly... (Businessman)

In addition to the provision of education and training in the workplace, it was suggested that this content should also be integrated into degree and other tertiary level management courses. A client respondent suggested employers would benefit from attending a bipolar/schizophrenia support group meeting in order to observe the similarities and differences in level of functioning of people with the same disorder.

Participants appeared undecided whether the proposed education of employers would be voluntary or compulsory. A community worker, emphasising the need to build

employer awareness, commented “you’d be surprised at how many employers may be able to turn that around.”

***Co-worker education.*** Respondent pointed out the need for workplace education to enable co-workers to appreciate the condition, have more knowledge and awareness of the issue and how to deal with a situation should one develop. It was suggested the government should provide a staff education program. One employer proposed this training should be mainstream training for general staff in the workforce using online training. It was pointed out education of co-workers would need to be done thoughtfully to avoid raising unnecessary concerns about safety risks. It was pointed out that more knowledge of conditions is needed:

...if people actually knew about it...not just that... if you have schizophrenia you're definitely gonna [sic] have this, this and this. Like it's not really the case. There's so many different levels of it. If employees knew more about mental illness things would be different. (University student)

An employer, who acknowledged he was unaware of the relevant privacy issues, felt it was preferable for co-workers to be aware of a worker’s psychotic condition and what to expect. It was considered fair that co-workers should know what to do or how to handle a situation should one develop. It was also considered that, to avoid co-worker dissatisfaction, they may also need to be informed about employment arrangements for workers who may be regarded as less productive than others in the workplace as well as the importance of their own role in providing the employment opportunity. Respondents

also pointed out that employee consent would be required regarding the manner and extent of disclosure of personal information to co-workers.

Employment consultants and case workers were seen to have a potential role to confer with and educate staff. It was acknowledged, however, that many people who enter the workforce choose not to use employment services, do not have access to a case manager and may decide not to disclose their condition to an employer. A community participant felt that knowing co-workers are educated and accepting would make people living with psychosis feel more comfortable about entering the workforce and reduce their workplace stress levels. One employer described successfully working with co-workers to bring about attitudinal change in an organisation, describing a learning curve in which co-workers move from a position of fear of the unknown to active acceptance:

What we've done is work with the culture of the organisation, with the other staff, ... and at first there was fear I think...of the unknown. How were they going to work with these particular staff members but now I've found that they actually embrace them and work with them and help them. (Employer)

**Increasing exposure.** In addition to education, it was felt more exposure of the community to people living with psychosis could help overcome social stigma and break down negative stereotypes. Participants suggested that to change beliefs and make a difference there is a need for more people to “come out” and talk about it openly, provided it is done appropriately and within reason.

The presence of a growing peer support workforce was seen to be bringing about positive change in the culture of working environments:

...before we came along, it was just the professionals and the people they're working on (laughs), so to speak, but now that we're there it's changing the culture a lot because they [health professionals] have to really watch the way they're talking, the way they're acting when there's a big, a growing peer workforce there as well...and it also helps them see that having a mental illness doesn't mean you can't succeed 'cause when they see us day in day out for years and years...doing stuff and achieving things...they change their opinion about having a mental illness you can't recover and you can't do things and you can't achieve. (Peer support worker)

Other means of exposure advocated by participants were advertising campaigns to normalise conditions, public disclosure by high profile people, more acknowledgement in the community of the “average person who is working and effectively managing their condition”, and inviting people with lived experience to participate in educational opportunities in schools. It was also suggested there is a need to share and showcase good news stories of effective employment support and of employees with lived experience of psychosis who are doing particularly well.

Opinion was divided on whether increasing the employment rate of people living with a serious mental health condition would increase community exposure and help overcome stigma. In regard to the potential effect of an increased employment rate on stigma, one respondent felt employment alone would be insufficient as the high incidence of non-disclosure in the workplace would restrict the potential impact of exposure from employment:

I guess it's being able to know whether you can pin-point those people [in the workplace]...and that's the whole secret hidden part of it...is whether it's getting disclosed to providers or the employers. (Client with schizoaffective disorder)

Some were uncertain, while others felt it would help to reduce stigma:

...what we've seen in the physical disabilities area with having people with deafness or other things employed I think has reduced a lot...people are not bothered by seeing someone with a physical disability, you know, whether it's a check-out chick that hasn't got much of her arms from there. I think people are used to that and it doesn't really bother them now and I think that's because they've been employed and you just get used to it. (Peer support worker)

Several respondents felt that more people coming in contact with people living with these conditions would provide the best and most powerful form of community education:

I think once someone meets someone with schizophrenia or bipolar and understands they can get stable, and they do want to work and they have dreams and goals like the rest of us....Once it's a little bit more common in your life, you know someone or you do a job like ours', you just seem to understand a lot more and accept any sort of weird little traits they have, or any sort of things they say and that goes with the disease. (Employment consultant)

Aah it [employment of more people with mental health conditions] would be brilliant. It would impact on social stigma because...[they are] in and around more

people and not behind their doors, because that's half the problem is that they're still hidden away. They're not in institutions anymore....they're behind closed doors. (Family member)

I think if it was managed well and there was [sic] good, positive outcomes in the workplace, I think it would be...one of the most powerful ways of reducing the stigma...It's a bit like a lot of discrimination...it's easy to do when it's not attached to a personality but as soon as you put a personality and a real person behind that image it changes people's perceptions. (Business manager)

An employer shared that through exposure to employees with schizophrenia the business owners and staff had gained a better understanding of the condition and that this experience had changed her thinking about their ability to work:

...all the staff that we have had not had any dealings with anyone with schizophrenia and yeah they've realised they're not scary people. They can work. They can do tasks that are set out for them and so I think just a better level of understanding...and appreciation that these people are like you and I [sic]- if they're medicated that is - and we've only seen them through work medicated so we don't have any reason to say otherwise. They're just normal people...it's helped us to understand the whole mental health issue incredibly. There's often a stigma attached but I think of it differently now because I understand a little more than I ever did and realise that these boys are-in our case we've only been with young men-but they're just normal guys just trying to get through life and they've

been thrown some hard knocks along their way but they can get through it so yeah

I would highly recommend it and I'd say give it a go, give it a go. (Employer)

Participants identified a number of positive community impacts of exposure to employees living and working with psychosis: people would see them “doing this stuff”; people admire people with disabilities who go out there and “do something”; it provides opportunity for learning about conditions and to learn things from each other; it would teach others to be better team players and benefit everybody; and others would learn that people with a serious mental health condition can do things and fit into society. It was also opined working alongside a person with a condition normalises it and makes it a personal experience rather than just knowing about it intellectually. It was also felt that it would increase acceptance and awareness “that they are just ordinary people with an issue”.

On the other hand, some participants felt employment could “fail disastrously” to change perceptions: co-workers might blame the person for everything and feel negative towards each other; others might be unable to relax, feel wary and have difficulty accepting it. It was expected a negative reaction is more likely to occur if the person is known to have a serious mental health condition and there is no prior personal relationship. Factors seen to mediate positive culture change brought about by employment were: effective management of the condition; willing and accepting employer and co-workers, and a positive employment outcome.

***More Disclosure.*** A comprehensive discussion of issues pertaining to disclosure was provided in Chapter 9. Participants indicated that more disclosure is needed, due to the less visible nature of the condition, in order to increase public exposure to psychosis. Participants felt that in order to “change beliefs and make a difference” more people need to “come out” and talk about their condition openly. A community respondent bluntly suggested people need to “get over” the fact they might be judged and just be completely open, although others indicated more social acceptance is needed before people would feel comfortable enough to be transparent with employers.

Some suggested a need for “some heroes out there”, referring to high profile people who are willing to talk about their condition. There was also a need expressed for more public awareness of the “average person” who is working and managing, in order to provide more attainable role models for the general public.

It was also suggested that in an ideal world disclosure would not be necessary:

You know you shouldn't have to go to work and *disclose* that you've got something because that automatically again separates that person. I mean they have to disclose, I understand that, so they get that support, but we're talking in an ideal world you don't have to disclose because it's really not an issue. There is someone you can go to and say, “Well, you know what, I'm not so good at that but I'm really good at this, this and this.” (Employment consultant/psychologist)

**Activism and advocacy.**

Non-government organisations concerned with mental health were seen to be making a positive impact in educating the public and promoting the anti-stigma message,



more particularly in regard to the so-called “lighter” forms of mental health problems such as anxiety and depression. People with lived experience of psychosis were identified as playing a key role in promoting and supporting anti-stigma campaigns and political action to bring about change.

An independent jobseeker who expressed frustration in trying to explain his experience of bipolar disorder to an employer expressed need for a mediator with good communication skills to negotiate with employers.

...there needs to be some sort of communicator between the employer and the employee when it comes to mental illness because there's no middle mutual person. There's just you, the employer and whatever their perceptions are...

(Employee with bipolar disorder)

A family member felt that more people living with schizophrenia should know about the Ottawa Charter and stand up for their right to articulate their own support needs. A peer worker felt the only way to challenge attitudes among service providers is to introduce the consumer perspective. The presence in the workforce of employees with lived experience was seen as an important means to reduce stigmatising behaviour and change the culture within an organisation. It was also suggested there is a need for more active support, including free legal services, for people who may have been victims of workplace discrimination.

### **Societal Attitudes and Reactions**

**Desirable attitudes.** Respondents felt societal attitudes and reactions need to change. A politician stated, “I think firstly we have to change peoples’ attitudes...I really

think it's all about people's attitude..." An employment consultant described this shift as "some sort of structural change in the perception of people who have mental illness". Carers attributed stigma to "a culture that we've all been brought up in" and said they would like to see a more positive attitude change towards *anybody* with a disability, but particularly in the mental health area. It was felt there needs to be more willingness to provide opportunities for people, and that the resultant social interaction would enable people to flourish. Clients felt people who reach the point where they disclose a condition to an employer need to be taken seriously and given the same opportunities as others, to better themselves. It was also felt society needs to be willing to make structural adjustments where necessary to accommodate everyone in the workforce. Respondents referred to the need for less judgemental attitudes and more tolerance; understanding and acceptance; compassion; inclusiveness; equality of opportunity; encouragement; hope and optimism; respect and sensitivity. There was however also a sense of hopelessness and scepticism expressed about the magnitude of changes that would need to occur. A family member cynically commented, "It's a whole shift in the whole human race (laughs). Good luck with that!"

**Government attitude.** It was felt the government needs to take the lead in attitudinal change and providing opportunities:

I think the government needs to stop thinking...like stop going, "ah they're just the minority" because they need to be taken care of. They need to be given the opportunities because society won't give them the opportunities so the government needs to be the leading force behind, "No it's not okay to treat these

people like this”. If the government doesn’t stand for it, society can’t stand for it.

(Community member)

A carer maintained there is a need for serious mental illness to be accepted, and managed on the same level as any other life-threatening illnesses. In terms of government employment services, a former employment consultant suggested there needs to be less of a “numbers game” and more individualised support and encouragement provided. An employment consultant considered that in order to achieve true integration mainstream employment services should have the capacity to assist *all* clients, including those with psychiatric disabilities. A community member proposed the government, rather than looking for short-term solutions to unemployment, should make investment in longer-term solutions such as funding business enterprises employing people with mental health conditions until they become viable businesses.

### **Positive client attitudes.**

Participants emphasised the need for clients to adopt a responsible attitude to their own self-care and management. A client participant suggested the need for people living with psychosis to allow others to get to know them as a person as a means to overcoming stigma:

If they find out you got a disability they don’t want to know ya but we’ve got to overcome that and get them to *know us*. Know that people with schizophrenia are not dangerous if they’re on their medication, doing appropriate things, getting appropriate support... (Client with schizophrenia)

The need to maintain a positive attitude in the work situation and work with others as a team were also mentioned as means to elicit collegial support. It was felt employers with personal experience of mental health issues may be more likely to hire others with mental health conditions, as they have more understanding and are likely to be more forgiving.

Client attitudes towards disclosure varied (see page 186). Notwithstanding the risks of stigma and discrimination associated with disclosure, a number of participants advocated the advantages of “coming out” about a condition. A young community member stated:

I think that people with mental disabilities need to just get over the fact they might be judged and they just need to be completely open about it. Otherwise that, in itself, I think is a barrier to their employment. (Community member)

**Positive health care worker attitudes.** Positive attitudes towards work on the part of health professionals were seen to be a key factor in vocational recovery. Clients were clearly attuned to the attitudes of their treating specialists and looked to them to provide hope for recovery. Although some psychiatrists were described as “fantastic and really understanding what recovery is about”, others were described in less positive terms. Client participants pointed out the need for a more positive, optimistic and encouraging approach on the part of health care workers. A client with schizophrenia contended: “There are psychiatrists and there are psychiatrists. There are psychiatrists who have helped me in overcoming my problem and there were psychiatrists who couldn’t have given a hoot.”

The presence of peer support workers in the mental health workforce was also seen to play an important role in changing the attitudes and behaviour of health professionals. Employment of peer support workers was perceived to have a positive effect in changing the culture of mental health treatment settings. It was felt the speech and actions of health professionals and others in the work setting comes under closer scrutiny, and co-workers have the opportunity to observe people who have recovered, functioning effectively in a work setting. Peer support workers in the sample displayed a positive and optimistic approach to recovery and were seen to provide a positive role model, guiding and providing hope to other consumers. The presence of peer support workers in the mental health workforce was also seen to play an important role in changing the attitudes and behaviour of health professionals. Employment of peer support workers was perceived to have a positive effect in changing the culture of mental health treatment settings. It was felt the speech and actions of health professionals and others in the work setting comes under closer scrutiny, and co-workers have the opportunity to observe people who have recovered, functioning effectively in a work setting. Peer support workers in the sample displayed a positive and optimistic approach to recovery and were seen to provide a positive role model, guiding and providing hope to other consumers. One participant believed there is *always* hope, and while acknowledging her opinion had changed somewhat over time as a result of exposure to chronic patients, felt even these patients could participate in voluntary work:

...maybe that's something I wouldn't have said a few years ago but I do see people within the service that now have almost institutionalised unfortunately and

have digressed [sic] and are quite unwell so there would be a proportion of people, I do think, that are unable to work but maybe in a voluntary capacity, you know...just something where there's not a lot of stress on someone. (Peer support worker).

Peer support workers also talked about encouraging people to use opportunities to discover what they are capable of doing, "... it's just pushing them, you know, to take that risk and that's what recovery is about..."

It was felt following onset of a condition health professionals should not communicate a lowering of expectations due to their illness and that every attempt should be made to retain skill levels.

**Supportive family attitudes.** Several participants referred to the vital role of support of family, partners and friends in providing practical as well as emotional support, employment guidance and, in some instances, suitable work opportunities. Participants mentioned the vital role of family and social support to nurture self-esteem, encourage, support medication compliance, assist with transport if required, provide someone to talk to about the day at work, and to be a resource during relapse. Even for people living independently, family support was seen to be important during times of relapse. One client described family support like this: "It's yeah, no one factor in your support like your family...you can always talk to them about what's going on and they're always on your side..."

Families were also seen to play an important role in encouraging and motivating their loved ones to achieve. One participant highlighted the need for families to guard

against unduly lowering expectations and removing all demands. This participant also referred to a need for family and friends to be mindful of “knee-jerk” comments which may unwittingly undermine self-efficacy.

**Supportive community attitudes.** Respondents suggested the need for attitudinal change in the community in the direction of less stigma, and more understanding and tolerance of “people who are a bit different”. Participants felt there is a need for a more open view and greater social acceptance of people living with severe mental health conditions. A need was expressed for more inclusivity, community responsibility, willingness to treat people equally and provide them with the same opportunity. It was felt that there is a need for the community to see the person for who they are and not the disability, to adopt a non-judgemental attitude, and to exercise unconditional love and respect.

There was also an identified need for greater capacity for members of the public to deal sensitively with unusual behaviour in the workplace and a willingness to actively promote the integration and social participation of people living with these conditions. One participant felt this would require more empathy and “a massive shift in social conscience about who human beings are”. Although one participant described himself as “not a fan of inclusiveness” and another predicted “it’s not going to happen”, there were others who were strongly in favour and felt these values are congruent with the dominant ethos of Australian society:

I think it’d be wonderful in the sense that it would, and it *should*, reflect in, inclusivity of all types. Australia is a multi-cultural country...and we pride

ourselves on inclusivity and therefore I would classify mental illness as one component of inclusivity. (Educator)

A young client participant with bipolar disorder said wistfully, "...as to the general public understanding, or knowing or accepting, I think that would be good...one day." A community respondent felt there would be more capacity to respond appropriately to people with mental ill health issues "in a more caring society, in a society less bothered about the bottom line, less bothered about itself...actually supporting each other."

One community participant recalled how watching the movie *Mr Jones*, in which the main character has bipolar disorder, had elicited an empathic response. Teachers were also seen to play a role in inculcating respectful attitudes towards people living with psychosis.

**Positive employment consultant attitudes.** A former employment consultant emphasised that assisting jobseekers with psychosis is not a "numbers game" and that extra care and encouragement is required to build them up and ensure they find sustainable employment. A friend of a person living with psychosis felt employment agencies need understanding, sensitivity and compassion to fully appreciate the impacts of changes in job arrangements.

**Supportive employer attitudes.** Community members pointed out that employer attitudes *have* changed over the years and participants were hopeful that in the future more flexible leave arrangements for people living with fluctuating mental health conditions could be achieved. A respondent pointed out that significant change has occurred in employer attitudes towards pregnancy over the years and community



respondents expressed hope that a similar change could occur with respect to mental health:

P16: That reminds me when pregnancy...to be employed as a mother of a child.... the pregnancy laws...and people [co-workers] would say “Ah why is she... [entitled to special privileges] (laughs). It’s a similar sort of thing really isn’t it? So maybe in twenty years’ time, thirty years’ time it might evolve into something that is just normal.

P18: Yeah, but it takes a lot of time I think.

P16: Oh yeah...and it’s not really talked about either whereas pregnancy is.

P20: Quite taboo yeah.

P21: But wasn’t pregnancy taboo at one stage?

P16: Like with employers?

P21: For employers...so it’s progressed so shouldn’t we be able to progress on this issue too?

P16: I hope so. (Community members)

A client with bipolar disorder suggested having a supportive employer is a necessary pre-condition to disclosure: “If they’re supportive and you know they’re gonna [sic] be supportive, give them a hundred percent, don’t worry about it...but if they’re not supportive no don’t tell them a damn thing...cause they’ll hold it against you”.

Participants referred to a need for less fear, stigma and discrimination, less ignorance and bigotry. There was need for employers and senior managers to treat people

well, look after them and to understand and accept that people “can get stable, and they do want to work and they have dreams and goals like the rest of us”.

The following words were used to describe desirable attitudes in employers: open-minded, sympathetic, understanding, supportive, kind, flexible, forgiving, patient, open, and willing to take a certain amount of risk. Clients talked about the need for employers to accept that people with a mental health condition have something to offer and to provide equal employment opportunities:

...you got to get a *go* man, you’ve got to get an employer to give you a *go*... Throw the resumé away. Give a bloke a fair go. You don’t need to check up on people all the time. Resumsé, certificates all this stuff...give a bloke a fair go.  
(Client with schizophrenia)

...if we ever get to a point where people with a mental illness are disclosing that to potential employers, we have to know that it’s not going to be an immediate “Well, I won’t consider you”. We know that if we disclose, we have be taken seriously and given the opportunities that other people are given, so based on the idea of giving people an opportunity to better themselves. (Client with psychiatric disability)

It was also felt employers should be willing to allow workers to be unwell and return to work following periods of relapse, and accept people may sometimes take weeks or months to recover. It was also suggested employers with a better attitude may not expect

any extra funding as they would just want to do “the right thing” and what should be the norm:

It’s definitely not the norm now but that would be the ideal world for that [employment of people with psychosis] just to be normal, and that there would be two or three people with disabilities in every workplace and they fit in with everyone else and I think it would stop a lot of bullying as well because I mean I guess it is a sort of aspect of bullying in a way... (Employment consultant)

There was acknowledgement that this may be very difficult but needs to happen:

...employers need to be supportive and it’s hard ’cause they’re wanting to make their money and they’re wanting to keep the workplace as stable as possible so they may, instead of taking the easy way out, maybe...just having more of an open mind. (Employment consultant)

One participant commented employers should judge people on the work they do rather than on their condition. Another felt employers should not just look for output and should be mindful of providing a working environment optimal to mental health for all employees.

Participants linked better employer attitude with education. Many respondents referred to the need for employers to be educated and informed. There was also a need for employers with positive attitudes who have had good experiences employing people with these conditions to share these experiences with other employers.

***Corporate social responsibility.*** The view was expressed that as a society and as a community there is a need to take responsibility for people who do not have the same

opportunities because of their condition. One participant, relating his experience in New Zealand, said: “you’d be surprised at how many employers *do* want to contribute to the community and open their doors to people that have significant barriers to employment.”

There was reference to ways in which corporate organisations in Australia are already meeting community expectations regarding social responsibility. Participants referred, for example, to companies who deliberately leave some jobs open for people with disabilities or employ a quota of people with disabilities. Some responses seemed to imply these would be low-level jobs. An employer remarked, “I’ll draw your attention for example to [supermarket chains] who often employ people with disabilities to collect the carts and push them into the shop. I don’t know whether you’ve noticed it...”

There were also suggestions of ways in which companies could potentially fulfil their corporate social responsibility. One participant suggested that, rather than discriminate against people based on their mental health, companies should promote the fact that they are willing to employ people with problems and create programs that would help them overcome barriers. Other participants suggested that employers become an “employer of choice” or recognised employer of people with psychiatric disabilities, or sponsor people with psychiatric disabilities to create their own businesses. Further suggestions were to promote businesses that are affirmative employers of people with mental health conditions by using badges on products or via employment recruitment websites. Some respondents, however, pointed out that community attitudes may not yet be conducive to a company marketing itself as an employer of choice for mental health conditions. For further discussion on this issue see page 160.

**Supportive co-worker attitudes.** It was felt co-workers need to learn to become better team players, be willing to work together, learn from each other, help out and provide mentoring and support when needed. It was felt that if co-workers were aware that a person was performing to their capacity they would be prepared to assist, for the benefit of everyone, during periods when their colleague cannot work or be productive.

An employer explained that patience, understanding and unconditional acceptance on the part of the staff had yielded “huge” results:

I think it’s been a group effort that everyone, you know, understands the situation. The staff have seen, like we have, where they’ve come, what they’ve achieved in the time they’ve been with us so none of us expects huge things but we end up getting huge results because we’re patient, we’re understanding if that makes sense? (Employer)

A co-worker indicated that having the experience of working alongside a person with bipolar disorder had helped to normalise it for her. Co-workers in the sample felt that, in general, having more people successfully employed in the workforce would promote greater understanding and acceptance and help others deal with it:

I would think generally having more people successfully employed would help people accept, to help and deal with it. It’s a minor difference-in the same way that you might have a colleague who’s got epilepsy. You might have a colleague who’s diabetic and because you’re aware of that...imagine someone has an epileptic fit, you’re going to handle it and not be so traumatised and life goes on,

as opposed to sticking them in a corner and saying, “No, that’s too difficult to deal with.” (Community member)

### **Normalisation and De-Stigmatisation**

Participants at times referred to prevailing social values and the discrepancies which exist between social values and behaviours towards this group. The social attitudes and reactions considered most important in the context of employment support needs were understanding and acceptance. There was also a sentiment that societal attitudes and reactions need to change to become more inclusive, tolerant, respectful, compassionate, sensitive and non-judgemental. Responses expressed the need for people with mental health conditions to be accepted as human beings in the workplace:

You know who cares if they’ve got a mental illness or their nose is on the wrong side of their face or their eye is twisted?....I think it’s time that people took people on face value and their morals and the way that they have their ethics in [the] workplace...if they have all those standard things then why should it matter that they have a mental illness?” (Employment Service Provider)

Participants identified a need to remove stigma and for positive change in society’s attitude towards people with all types of disabilities, particularly mental health.

Respondents felt that society should not make an issue of disability, irrespective of the condition. It was suggested that individual differences in mental experiences should be treated in the same way as individual differences in physical characteristics:

...it would be...I have schizophrenia but this person has blue eyes. This person is two feet tall. This person is six feet. It's just that everyone is different and I suppose that is there, but I suppose we categorise that group *so much*...

(Community member)

One respondent said, "They have a mental illness. The person has a spot on the end of their nose. It's the same sentence", while another responded "There's nothing wrong with it."

Several participants questioned the definition of normality and who decides what constitutes normal. It was suggested that due to the prevalence of mental illness in the population, most people would know about it, have a friend or family member with a mental health condition, or have themselves experienced it, and therefore it should not be regarded as abnormal. One participant suggested stigma would be reduced if the experience of *mental illness* was integrated into a continuum of normal experience and that people experiencing psychosis were just conceptualised as being on a different end of the scale to what others experience. It was also felt this might "relieve a lot of people".

It was considered there is need to eliminate employer discrimination and increase understanding and acceptance of people with mental health conditions. People expressed hope that attitudinal changes would occur in the workplace. It was felt that people should be employed for their skills and that use of a support worker or absences to seek treatment, if required, be considered normal:

...in this utopia where the employer's gonna [sic] say "Well, I have two employees who aren't very well. Go and have a Syndol and have the rest of the

day off and get rid of your headache. You go home...have the rest of the day off and I'll contact your support, your back-up, make sure you're having your tablets" or whatever. This is in the future in this utopian world where there's no discrimination. (Community member)

Education was considered to be a key means to normalisation and de-stigmatisation. It was felt that normalisation should begin earlier on in peoples' lives, at school. Teachers were seen to have a role in inculcating into children that everyone needs to be treated with respect. It was felt that employers and managers should be made aware that a certain percentage of the workforce will present with these disorders, with varied occupational skills and experiences, and that this should be embraced as a normal aspect of workplace diversity.

In addition to education, it was felt that greater public exposure to psychosis would reduce stigma, provided the condition is well managed. Exposure was seen to include integration of people living with psychosis into the everyday life of society. It was felt "it's got this newness to it" and that more integration of people with these conditions into everyday social roles would help to normalise it so you "get more used to it, you don't get shocked when you see it. You don't think it's *not* something you're going to see". This would include employing people with psychosis in workplaces and for this to become a normal occurrence. Exposure in the workplace was seen to be of benefit as others would realise "they're not scary people, they can work, they can do tasks that are set for them" and would promote a better level of understanding. One employer with experience employing people with schizophrenia said: "as far as we're



concerned they're no different to anybody else" and "if they're medicated they're just normal people." A participant with experience working alongside a highly competent colleague with bipolar disorder commented, "there's almost a sense that it completely normalises it".

It was felt that in true integration, mainstream service provision would have capacity to assist all types of clients and it was felt this would have a normalising effect, as it places less emphasis on disability. Several participants pointed out people in the mainstream also have their challenges which are just different issues. It became apparent some people prefer not to use disability employment services as they just want to be "normal". It was felt that personal disclosure by service providers can help to normalise it:

And the admitting of it...I mean they [clients] have to share so much of their private lives with us really. I like to give a little bit back you know. But if I say my daughter suffered with anxiety or I had an aunty with schizophrenia, you know, just be honest that's in my life, they're really amazed. (Employment service provider)

It was suggested there is a need for more exposure in the public arena, that many people work all the time with varying range of medical conditions and that these can be managed. Effective management of the condition was seen to be essential to normalisation. There was a sense that disability should not be in the foreground or regarded as an issue, and that the focus should rather be on effective management of

conditions and provision of supports to optimise functioning. Creating a sense of independence was also seen to be important in the normalisation process.

Encouraging the general public to talk about psychotic conditions was also seen as a means to normalise it. Television adverts were seen to play a role in stimulating conversation on an otherwise taboo topic. It was also felt that careful use of language can help normalise mental health conditions. Participants felt words like *disability* should be avoided as it places people in a separate category, whereas in an ideal world *disability* is not really an issue and there would be no need for *disclosure*. A participant questioned the use of the term *consumer* to label people with mental health conditions and endorsed the use of more humanising and affirmative language such as *people with lived experience*. There was also a need expressed to avoid labelling people and the tendency to relate to people in terms of labels.

...there are some great people out there who really just want to be given a go and not label them as people with problems, you know, that they are quite capable of doing whatever it is that they want to do. (Employer)

### **Inter-Sectoral Collaboration**

Also discussed was the need for a willingness for various sectors to work together collaboratively to achieve positive outcomes. A need was expressed to close gaps that currently exist between services. These included: “a lot more overlap” between mental health and employment services; strengthening ties between primary health care providers and the employment sector; more working together and better understanding of the contribution each can make to achieving positive outcomes. It was felt that improved

employment outcomes, and avoidance of negative outcomes, could be achieved with a more co-ordinated, multi-disciplinary, multi-service approach where input and support is available from a number of different stakeholders.

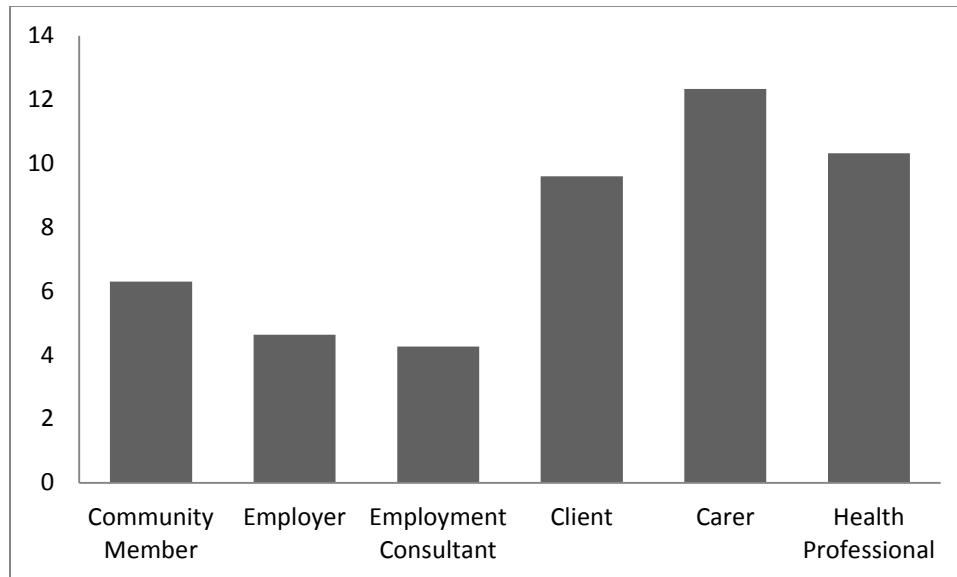
While there was evidence that attempts are already being made, it was suggested closer working relationships among health and employment providers would facilitate optimal utilisation of the specialist capacity of different providers to undertake necessary assessments and services for the benefit of the client. Another health professional commented on the potential value to clinicians of feedback provided by employment service providers on employment barriers and outcomes.

Participants identified the following key ingredients to success: “communication”, “working together”, “partnerships”, and “more integrated service delivery”, “negotiation” and “collaboration”. This would include agreement to facilitate the management of personal information and streamline information-sharing arrangements. One health professional pointed out not all mental health patients would need or want this type of collaborative information-sharing to occur and that this should be negotiated on the basis of individual client preferences.

### **Summary of Culture Change Needs**

The most frequently referenced culture change needs were for more awareness (270 references) and change in societal attitudes and reactions towards people living with psychosis (240 references). The need for public education (117 references) and more desirable attitudes (102 references) were major foci of discussion. The total number of

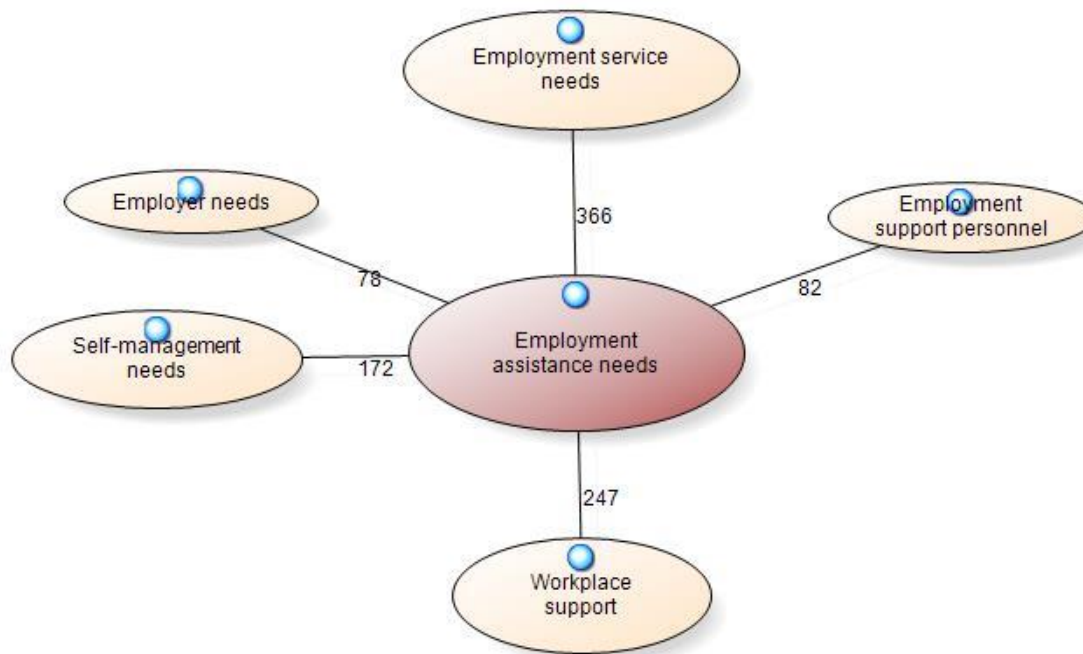
coding references to culture change according to stakeholder group is shown in Figure 46.



*Figure 46.* Average number of references to culture change according to stakeholder group.

## Chapter 12: Employment Assistance Needs

This results chapter focuses on references to the need for positive changes in the provision of employment assistance for people living with psychosis. The most frequently referenced employment assistance needs related to employment services; workplace support and improved self-management (see Figure 47).



*Figure 47.* Summary model of main employment assistance needs. The numbers entered adjacent to connector lines represent the number of participant references, or coding density, for each of the main support needs.

A more detailed analysis of employment assistance needs is provided in Figure 48. This chapter will focus on description of the contents of the most heavily populated nodes.

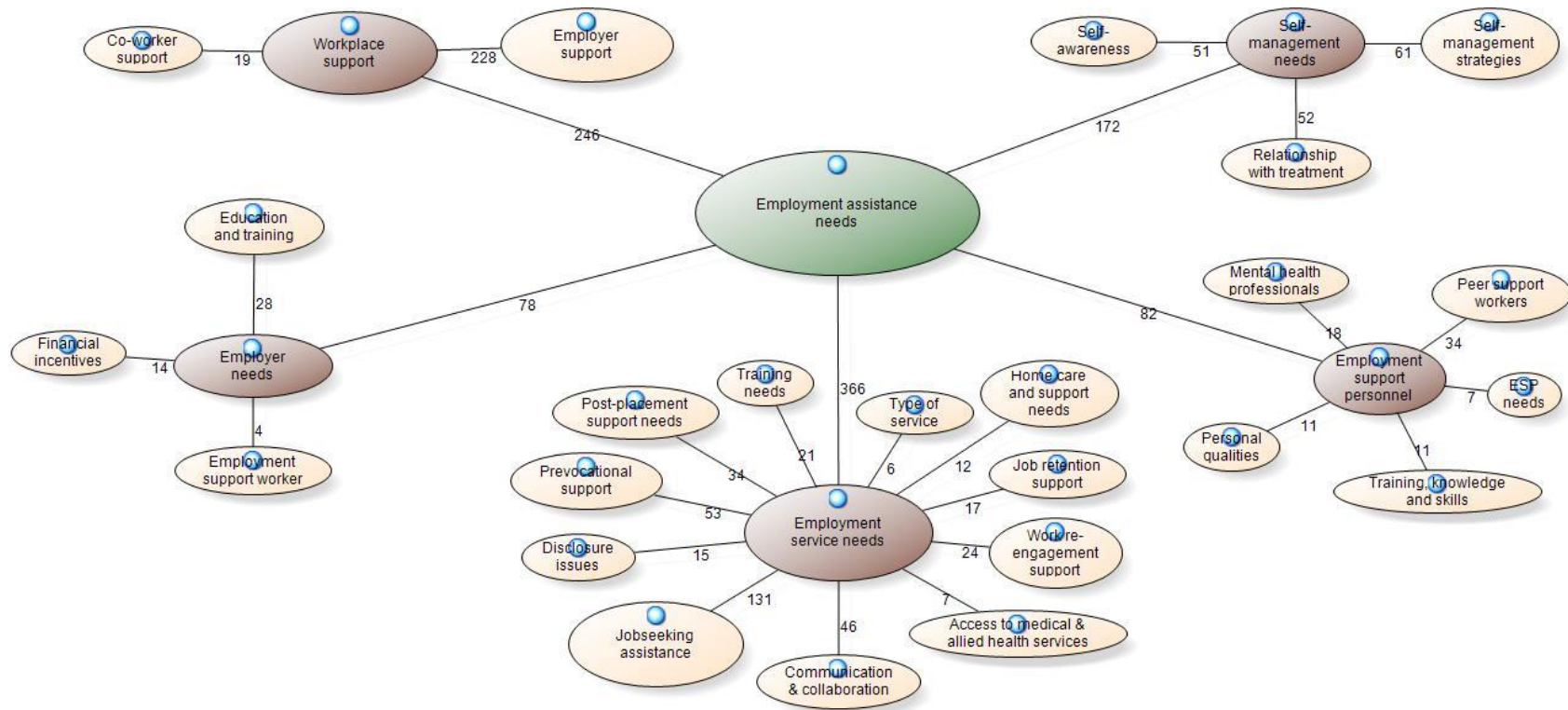


Figure 48. Second order analysis of employment assistance needs.

### **Employment Service Needs**

The most frequently referenced employment service needs were for job-seeking assistance; pre-vocational support; communication and collaboration and post-placement support (see Figure 48).

**Job-seeking assistance.** The most commonly identified job-seeking needs were in the areas of assessment, job fit and employment opportunities. In regard to job-seeking assistance, participants identified the importance of a good job match and a supportive employer.

**Assessment.** Participants discussed three types of work-related assessment: prevocational assessment, work capacity assessment and vocational assessment. Participants called for the assessment process to be “much sharper”, “more proactive” and more “in-depth”. There was a need expressed for better communication and collaboration between federal government agencies, state departments and private practitioners in order to better inform the assessment process and case manage particular clients. A private psychologist remarked:

Have I got the time to get in there and advocate and give them guidance and all the rest of it? ...and generally the answer to that is no. But the other part is do I want to do that? ...and yeah I do. I wouldn't mind having a bit more input. We have a lot of input in relation to doing Work Cover, return to work and things like that. We write reports, we liaise with the employer and the insurance companies. I can't see why we can't do that with a disability employment agency with

someone who's got a mental health condition. I think you could set that up and I think most psychologists would be on board with that. (Private psychologist)

*Prevocational assessment.* Clinicians felt work-readiness was a matter of clinical decision and judgement, and negotiation between the clinician and the patient, subject to any restrictions due to involuntary treatment orders. It was suggested this may include formal assessment of cognitive function, personality and vocational interests and that a collaborative effort may be required due to lack of resources to provide these services in the employment network. One clinician thought it was [social security agency's] role to establish work-readiness. Factors which health professionals deemed important in determining work-readiness following an episode include: stability of the condition; compliance with medication; support networks and personal aspirations. Some assessment needs identified by health professionals were for:

- Someone to *ask* the client whether they are ready for work. A medical practitioner observed, "I think, you know, to try and get people into those things [employment] is really about relationships...you need somebody that can say "Are you ready?"
- Assessment to determine levels of job readiness, skills and shortfall in terms of gaps in skills, with provision of training.
- Accurate multi-disciplinary assessment with focus on potential.
- Neurocognitive assessment. This might be helpful to identify strengths and weaknesses for purposes of arranging a suitable job match.



- More than one interview to determine work-readiness due to the need for monitoring over a period of time to determine stability of the condition.

*Work capacity assessment.* Respondents referred to the importance of accurate assessment to determine the degree of disability, level of education and training, skills and capabilities with a view to finding appropriate and meaningful employment. One employment consultant pointed out the wide range of variability in work-related support needs among people with the same diagnosis and hence the need for individualised assessment. The importance of accurate and reliable assessment of the client's condition, capacity to perform the job, potential impacts in different types of work situation was also perceived to impact the longevity of the job as well as being important in terms of an employer's confidence and willingness to employ a person. There was a perception that this would require "some serious psychological work".

It was felt assessment of work capacity needs to be a collaborative process involving negotiation between the client, employment officers and mental health professionals. A psychologist suggested that a multi-disciplinary rather than purely medical assessment would help identify potential and be more in keeping with a recovery approach.

An employment consultant suggested assessment for mental health conditions should be more comprehensive and consider all the factors that impact on their life. A psychologist suggested the importance of mood assessment. Another psychologist felt that factors to consider in assessing work capacity would include what the person feels they want and are capable of doing, and matching that with the clinical features, past

history and course of the condition. Yet another psychologist indicated safety issues would need to be assessed on a case-by-case basis. A peer support worker emphasised the need to assess the routines a jobseeker may need to stay healthy and avoid relapse, and arrange work around this lifestyle. In particular, it was felt the number of work hours and scheduling of work must take into account the need to attend medical appointments and maintain a routine conducive to maintaining mental health.

In addition to identifying barriers, the assessment needs to recognise strengths, abilities and positive attributes. An employment consultant observed, "...we're always looking at their weaknesses. We need to look at their strengths." One participant diagnosed with schizophrenia highlighted the need to focus on strengths and abilities:

You know as long as I'm fit I can pick up timber posts and that with my hand, you know. I'm pretty fit. If you put a bloke out on a property, on a station, there's farm work. You can pick up timber posts and there's good money in it... (Client with schizophrenia).

An ex-employment consultant indicated that other aspects requiring assessment were presentation, attitude, dependability of the client and the employer. It was suggested that assessment would ideally involve observing and monitoring people in different work environments. It seemed that assessment was envisioned as an ongoing process that extended to the post-placement period rather than a once off assessment. It was also pointed out that work capacity can be significantly influenced by the nature and support available in the work environment:

...you never really know until someone's doing it too. Like it can depend on whether they have a really good boss or a supportive colleague and they can love attending work and that can make a difference and they can want to work more than thirty hours then or they may actually find it really challenging to be there and want to reduce it down to twelve or to six because it doesn't really feel that safe there. So they're just doing a little bit to make a little bit more money and then retreating to a safe home situation...hard to tell. (Psychologist)

*Vocational assessment.* The need was identified to help person find a job and work situation (niche) where they can fit into society and that elicits passion. There was a strong call for more in-depth vocational assessment. Participants requested access to aptitude testing with a view to optimally using their aptitudes, skills and experience. The assessment process would need to assist the client to clarify their personal interests and desires as well as match these with characteristics of the job and work context in order to elicit enthusiasm to participate.

I think you have to find out what that person is interested in. We're all interested in different things, aren't we? And if you can find out what they're actually interested in, well, that helps to start with, to give them training in whatever they want to do. I think you're half way there then. (Community member)

A client with bipolar disorder explained, "you have to find a bit of passion for what you do. The right job and right workmates and stuff like, you know". A former employment service provider emphasised the importance of "recognising their abilities, not what other people think they should do...but what they can do and what they want to do" while a

psychologist pointed out a person that really enjoys their work would “be motivated to get up and do it.”

Participants endorsed the useful role that psychologists can play in assessment of aptitudes and abilities and suggested that this should be done, and feedback provided, at an early stage of the condition.

P56: I think it would be a good idea when people first started with some sort of mental illness if they give them an aptitude test and check them out as to what kind of jobs they’d...

P56: That’s right,

P52: ...be suited to.

P56: ... that’s right, that’s a good point. (Clients)

A common theme (34 references from 18 sources) was the need for extra care to ensure good job matching in order to ensure viability and longevity of the job.

Participants considered that a good job match would need to take into account individual differences such physical characteristics, interests and intellectual ability.

I think that pretty much they’re all capable of working. It just depends on getting the right job at the right hours...it’s just about making a good fit between that person and the actual occupation they’re going to have. (Peer support worker)

Several participants emphasised the crucial importance of career choice and a good job fit for ensuring sustained interest, motivation and longevity in the job. A family member said: “[Name] wouldn’t survive in an office - there’s no way- but [he] would be out of his

mind on a conveyer belt, so it would be a matter of finding the thing that that person loved the most...”

It was felt jobs need to be matched to skills, strengths, attributes and confidence levels. Other factors that may require consideration include ability to meet the physical demands of the job, length of the working day and need for breaks and adequate time to re-charge; comfortable, safe and supportive working conditions; passion and enjoyment of the work; compatible work mates; levels of stress and pressure associated with the work; preference for solitary work; nature of work, reasonable travel time, and the costs and risks associated with any work-related errors or incidents. Clinicians and employment consultants suggested that there needs to be a gradual transition to work with graded increase in hours. However, a client participant contended this approach was not appropriate for everyone. Participants suggested there may be a need to match working hours to the daily pattern of fluctuation in symptoms and drug effects. A psychiatrist cautioned shift work can be “very problematic” for people with bipolar disorder as disruption of the sleep cycle and medication routine, and sedative effects of medication may render them vulnerable to relapse. A carer participant, however, described her friend’s night duty role as the perfect job for her, suggesting that the determinants of successful work outcomes are complex. It was also suggested work should be tailored to the lifestyle required to stay well and not vice versa. An ex-employment consultant also suggested there needs to be a match between the goals and values of the individual and the company, and that the dependability of the employer as well as the prospective employee needs consideration. An employer suggested larger

companies offer a wider range of jobs and therefore would have more potential to provide a good job-fit. Others suggested matching type of work to the nature of the condition.

There was a suggestion that persons with certain types of disorders may be more suited to certain types of jobs than others. One client suggested that people with bipolar disorder may be more suited to a creative job or one that “allows them to be themselves” while a businessman suggested that people with bipolar disorder were well suited to jobs requiring extraversion such as sales.

***Employment opportunities.*** There was general support for an increase in the number and range of suitable employment opportunities available to people living with psychosis. A need was expressed for more work opportunities in competitive employment settings in which the employer is willing, if necessary, to offer flexible working hours, modified work roles and the option of job-sharing, particularly for people returning to work following a major episode. Self-employment options were also suggested including business franchises set up and operated by people living with psychiatric conditions and supported by government subsidies or sponsored by large corporations.

There was widespread recognition of the valuable role that employees with lived experience of psychosis could play within organisations providing services for people living with psychosis, due to the empathy they can bring to the situation. There were disadvantages identified with peer-specific roles, however, and it was felt employment of people with lived experience in regular work roles within organisations would be preferable.

Unpaid work trials were suggested by several participants as providing opportunity to gain work experience and demonstrate value without placing any obligation on the employer. These were, however, not widely endorsed due to the negative impacts of potential rejection and what one participant described as a need to ‘job hop’.

Transitional employment opportunities offered in the Clubhouse model were seen to provide some benefits in terms of skills development. However, these employment opportunities were not fully endorsed by participants due to the time-limited nature of the employment and the fact that, irrespective of work performance, there was no prospect of ongoing employment. In general it was felt that transitional employment options should not be time limited.

There were several participants who felt some people living with psychosis would not be employable in mainstream employment and endorsed sheltered workshops and business services as a stepping stone to employment. Most participants, however, were of the opinion people living with these conditions should be accommodated in mainstream employment. One participant contended:

If they can work in a sheltered workshop....why couldn't they do the same job in an unsh[eltered work situation]....it's still four walls. You know you're doing [working within] four walls and you've got a supervisor so what difference does it make where it is? (Peer worker)

There was strong support for the concept of social firms as a pathway into employment, provided the employment opportunity is ongoing, employs people with and

without mental health conditions and pays award wages. Participants also felt a need for financial sponsors to create businesses that would be more tolerant and willing to accommodate the needs of people living with severe mental health conditions. It was felt the support and camaraderie which such social enterprises can potentially provide would be an advantage of this type of employment:

...their employers will actually know where they're coming from; they'll have some sort of idea. So if we could create some sort of an employment agency and an employment business for people with that [mental illnesses], I think they'd find it much easier...I think you'd find a lot more people in work than out of work. You'll find that people'll want to go to work because they'll want to see their mates the next day just to find out what the hell they did the night before.

(Client with bipolar disorder)

Respondents did, however, identify possible risks of stigma and limited choice of employment roles associated with this option. Volunteer work was also seen as a good option for people who may not be capable of competitive employment.

### **Prevocational support.**

Participants noted the high level of prevocational support needs commonly associated with severe mental health conditions, such issues such as homelessness and co-morbid substance abuse. There was a sense that extra time and care is required to address these needs in order to achieve sustainable employment outcomes:

I also have met people who have the desire and in some cases don't have an ability yet...so it may be that they really want to [work] but there's a lot of



foundation work that needs to be undertaken to develop the skills and the life skills and the routines and patterns of behaviour to be able to maintain work at all... (Psychologist)

It was felt much foundational work may need to be done to stabilise accommodation, improve grooming and personal presentation, communication skills, stress management skills, self-regulation and establish supports so that protective factors are in place and the person is not adversely affected by the experience of working. Other pre-vocational needs identified were client-centred career counselling as well as the need to develop physical fitness and life skills. There were respondents who advocated cognitive remediation training as a prevocational intervention through use of computer-assisted training packages.

There was also a sense that for some people with long term mental health conditions support may be needed to improve their motivation to work. Respondents emphasised the importance of respecting autonomy of the individual in work-related decisions, including the type of work to be undertaken. It was suggested in order to feel motivated to work, clients may need to be encouraged or “find a bit of passion” by developing an awareness of their interests, abilities and goals. It was also felt building self-confidence would build impetus needed to enter the employment sector. Benefits counselling may also be required to explain implications of work on social security entitlements and provisions for reinstatement of entitlements if necessary.

Disability employment consultants indicated that funding levels need to take into account the often substantial prevocational support needs of this group. A rehabilitation

consultant suggested that prevocational support should commence before people leave hospital: “I think there should be something, some form of program, that picks up a client from rehab prior to taking them to an employment service...”. The introduction of rehabilitation vocational specialist roles in the mental health service was suggested as well as provision of programs to facilitate transition to work “ instead of just straight from being very, very sick to looking for work”.

Medical practitioners, in particular, were seen to have a very powerful influence on people’s decisions to return to work. Psychologists and occupational therapists were identified as potentially playing a role in pre-vocational preparation by assisting people identify and overcome their individual barriers to employment and facilitating return to work. Non-government not-for-profit community organisations were also seen to be well positioned to offer prevocational programs to develop work-related skills, stamina and routine.

A number of participants referred to voluntary work as a pathway to employment and felt more recognition should be given to the value of volunteer work. Volunteer work was seen as a good alternative to paid work as it provides a sense of contributing to the community, an opportunity to form social relationships as well as the potential to transition into paid work. Voluntary work was also considered a possible option for more severely impaired people who may not be able to participate in mainstream work.

**Training needs.** Participants commented on the increasing need for qualifications in order to meet job requirements of advertised positions. Participation in study or

training was seen to provide mental stimulation and promote social integration. Training was also seen as necessary to prepare people for work and develop work-related skills.

Various types of training needs were identified. Training in communication skills was seen to be important to facilitate social adjustment to the workplace and to enable employees to clarify work priorities and expectations. It was felt that a training course on communication skills for the workplace should be offered and available to all employees, not just for people with mental health issues. There was also a perceived need to introduce short courses on volunteering; to upgrade computer knowledge; and to develop job-seeking and work skills. Some professional employees living with psychosis were also perceived to need support to meet mandatory professional development requirements.

Client participants expressed the need for access to training opportunities. Training options considered helpful included on-the-job training, short courses, traineeships, cadetships or apprenticeships with opportunity for ongoing employment. Various modes of delivery for training were suggested. It was felt prevocational training could be provided in treatment and community settings. Participants raised the need for easier access to computers. Some participants with lived experience of psychosis indicated participation in formal education and training options such as university and technical and further education (TAFE) courses. One participant felt that availability of a senior student to act as a mentor would have been helpful to assist with his university studies.

**Facilitating disclosure.** It was considered reduction in stigma associated with psychotic experiences would increase people's willingness to disclose conditions. People appeared to be more likely to disclose their condition to a supportive manager or co-worker or someone with personal or family experience of a mental health condition. Self-acceptance of a condition also seemed to play a role in willingness to disclose. A client with bipolar stated, "...it [disclosure] doesn't faze me. I don't see myself as different from anyone else out there".

A non-medical approach to disclosure seemed to be the preferred approach with focus on impacts of the condition couched in non-clinical terms. One participant emphasised the need to be careful in choice of words when disclosing a condition:

...when we go to potential employers with my disability employment provider, we don't disclose what's going on right in the background. Like we sort of say "He gets a bit of anxiety and a bit of depression." We don't even say depression now, we just say a bit of anxiety. We don't say, "He can go into full blown psychosis." (Client with schizoaffective disorder)

One health professional stated that disclosure to an employer needed to be done carefully and diplomatically without using the situation for leverage or as an excuse. A client respondent shared that he found it helpful to inform his colleagues of his tendency to become frustrated by management.

Although there were exceptions, employment providers and community members for the most part recognised that where a client did not wish to disclose their condition to others this should be respected.

**Better communication and collaboration.** Open communication and good relationships with all relevant stakeholders were seen as key factors to achieving successful employment outcomes. A need was expressed for better connections and working together between various agencies providing support. It was pointed out a client may be accessing support from multiple agencies and it was considered important that “everyone’s on the same page” to ensure consistency of direction. In some instances it was considered necessary to contact agencies such as probation and parole offices and their treating psychiatrist in order to “get the picture”. It was also seen to be important that agencies support one another by providing information on the scope of their services and supporting each other should the client’s condition deteriorate.

...in the perfect world the employment consultant, the social worker, [social security agency] and the family would all sit down on a regular basis in the same room with the client and we’d discuss what we were doing, what we thought was right, what was wrong, and what was working. (Employment consultant)

It was suggested that local employment initiatives may promote better communication between the various stakeholders.

Participants suggested an improved employment service model would involve more collaboration and more integrated service delivery between primary mental health providers, employment services and social security. There was evidence that co-location facilitates collaboration and integration of services. Centralised case management forums for clients with a specific range of needs, arranged by a central agency, were also suggested.

The need for good communication between the employee and their treating health professional was also suggested. Mental health case managers were seen to have a vital role in negotiating employment options as part of recovery planning. Clinicians expressed a desire for feedback from employment service providers on employment successes and failures, perhaps as a means to seek reassurance that pathways are in place to provide adequate support. Clinicians in the mental health service felt that it would be interesting and that much could be learned from the feedback of employment consultants on their client's public presentation whilst working or seeking employment and their work-related barriers, successes and failures. It was felt that closer co-operation between stakeholders would enable specialist assessments such as cognitive and personality functioning to be undertaken by agencies which have the required resources. The need was expressed for a more collaborative and stream-lined approach to consent and exchange of relevant information in regard to employment-related activities. One clinician cautioned, however, that in the interests of privacy, information-sharing should be restricted to circumstances where such combined assistance is deemed necessary.

Employment consultants referred to their role in facilitating engagement with general practitioners and access to psychological intervention through a mental health care plan. A private practicing psychologist referred to a need to overcome time constraints in order to communicate effectively with other stakeholders, reflecting "...it's about finding that time to communicate with everybody for the benefit of an individual." This participant suggested that funding be provided for psychologists to consult with

employment service providers and write reports regarding clients' employment support needs, much like work currently undertaken for Work Cover.

One employment consultant emphasized the need for open communication between the employment provider, employer and participant, stating, "It is all about communication". It was generally felt employers would benefit from awareness and indeed may expect to be informed of the jobseeker's background, by a person who has sound knowledge of the person over a good time span and can advise where they would fit in. Communication with the employer from the employment agency would promote understanding of the employee's situation. An alternative suggestion was for a disclosing client to provide a letter for the employer, from his/her treating specialist. It was felt the manner of disclosure is critical and that the focus of communication should be on the functional impacts of the condition rather than providing clinical information. An employment consultant identified the need for open and honest communication with employers as well as the importance of the relationship between agency and employer. Key ingredients were trust on the part of the participant as well as the employer, the need for the employer to be open and flexible, and the need for frequent contact between the agency and employer especially during the first twenty six weeks. From the employee's perspective, the employer would need to be approachable.

The employment consultant was seen to play a role in educating the employer to overcome the 'fear factor' and eliminate misinterpretation, providing information on employment support needs and being available to provide back-up support when needed. The need was expressed for a support worker who can collaborate with an employer to

ensure a good job match and provide an appropriate level of post-placement support, with graduated withdrawal of support. Respondents felt that some employees may need a sort of “communicator” or “middle mutual person” between the employer and the employee. One respondent suggested an employer should be advised of how to identify and respond to early signs of relapse. Employers need to be informed of appropriate contacts within mental health services who can be contacted should the need arise. Some participants felt that honest and open dialogue between the prospective employee and employer was important whilst others felt the risks of discrimination would preclude disclosure.

**Post-placement support needs.** Post-placement support was identified as important for job retention. Participants recognised that it takes as much effort to retain a job as it does to acquire a job. It was suggested that there is a need to introduce more support into the workplace. The need was expressed to maintain some sort of connection with a person after commencing employment, described as “a bit of a safety net”. A social worker mentioned need for a support worker to support graduated increase in responsibilities and withdrawal of support.

It was felt that post-placement support gives employers a sense of “comfortableness” that there is someone else supporting an employee while everyone finds their feet. Participants suggested that post-placement support may be provided by employers, employment service providers, an externally contracted specialist worker (including peer support workers), case workers, social workers, mentors or volunteers. It was identified that post-placement employment support may take the form of onsite support and/or off-site support. A client participant in current employment expressed



appreciation for the one-on-one post-placement support he had received on site from his employment consultant. Other participants favoured accessing employee assistance programs provided by their employer. A client participant with bipolar disorder suggested the need for “real” support such as employer subsidies or assistance with mediation between the employer and employee.

Contact between the support person and employer, especially in the early stages of placement, was seen to be important for purposes of building a relationship and providing support to the employer. In particular, it was felt that employers need to be aware of likely impacts of the condition, suitable employment roles and support needs, including how to identify early signs of a deterioration in their condition in order to prevent the downswing from progressing too far. It was also felt that both employer and employee should be aware of contact details of the supports available to assist them.

Participants suggested that various types of post-placement support may be required: to learn the job, liaise and negotiate with the employer, talk things through if something is getting out of control, develop problem solving skills, cope with stigma or discrimination in the workplace, and debrief in the event of job failure. It was suggested that a support worker could facilitate adjustments to workloads or responsibilities if necessary to ease the employee into the workforce without causing undue stress. There was also a call for more organisational support and employee support programs within the workplace. The need for workplace adjustments is discussed in more detail on page 319.

Individuals were seen to vary in terms of the level of post-placement support required. It was suggested that gradual withdrawal of post-placement employment support services could occur once the employer is satisfied the employee is able to manage tasks. Although participants identified that formal support may need to be extended, several expressed the view that it should be time-limited to foster a sense of independence, with the option to re-engage with support if necessary in the event of a relapse.

Family and carers were also seen to play an important, yet generally unrecognised, role in providing a stable home environment, practical and emotional support and strengthening resilience by supporting the development of work-related coping skills and encouraging perseverance in the face of setbacks.

### **Employment Support Personnel Needs**

Opinion was divided on whether employment services should employ health professionals as part of their service. In relation to employment of mental health professionals in employment services, one participant suggested:

I'd rather see someone who [had an] employment background and just [had] training in mental health....they get *clinician-saturated*...all this time in hospital, and then they've got a case manager, and it's all about the illness. We just want to move people away from constantly thinking they're someone who's sick that needs to be treated all the time. Having a clinician is like saying "Ah well you need a clinician on hand whatever you do in your life", you know. If you're

getting a job, you need to have a clinician sitting there the whole time... (Peer support worker)

There were, however, some employment consultants who indicated they value the onsite support provided by health professionals. Clients were in favour of the employment of people with lived experience of a mental health condition in employment services.

Employment service provider support needs were deemed important aspects of overall employment support needs. Respondents considered that employment consultants need an appropriate level of training to enable them to provide a quality service.

Clinicians felt that employment consultants need better assessment skills to determine what people can do and where the gaps might be, as well as awareness of the influences that employment can have on mental health conditions. Employment consultants felt that in-depth and ongoing training in mental health is vital, as well as support and mentoring. Employment consultants themselves expressed a need to increase their mental health knowledge, including ability to identify early signs of relapse: “If you know what to look for, you can get in there and deal with it before it even gets to the point where they’re going to lose their job.”

The need for good working conditions, adequate holidays and self-care for employment service providers was mentioned as an antidote to reported high staff turnover and burn-out in the industry. Self-care includes acknowledging even small achievements, as stated by this former disability employment case worker/psychologist: “I think this is really important in the field...to celebrate everything.”

**Positive qualities of employment service providers.** Personal qualities identified as important in employment consultants included: genuine caring, belief in the client, honesty and courage to face situations without embarrassment. A former disability employment case worker/psychologist advised: “Don’t *not* do something because you’ll feel embarrassed...Just feel embarrassed and do it anyway.”

Clients expressed a preference for an employment consultant who is knowledgeable, non-discriminatory, listens rather than speaks and encourages the person into something they want to do, rather than pushing them into something they don’t want to do. It was also considered important that an employment consultant be a good communicator who is good at educating and explaining things to other people. Other characteristics identified were the need to be compassionate yet tough when necessary, as well as being friendly and easy to talk to. It was felt that employment providers need to have a deep understanding, and that ‘consumers’ consulting with ‘consumers’ might help to better understand their needs.

### **Employer Needs**

It was generally felt the government would need to support the training of employers as many jobseekers living with psychosis do not use employment service providers or have a case manager, and seek work independently. One employer felt this information should preferably be sourced from within business and industry and be delivered by other employers who had achieved success in this area.

Participants considered that providing employers with information relevant to managing an employee with psychosis in the workplace would be helpful and contribute

to a positive outcome. The types of information deemed helpful to employers included how to pre-empt adverse workplace reactions, early recognition and appropriate response to signs of relapse, contingency plans and persons to contact in case of an emergency.

**Workplace Support.**

A community member suggested that radical reorganisation of the workplace would be needed before significant change could be expected in the employment of people living with serious mental health conditions. The most heavily referenced needs were for employer and workplace adjustments. The main workplace support need was for management support. Having people around who understand the condition was seen to be an essential aspect of a supportive work environment. It was suggested that larger companies should be encouraged to provide employee support services within the workplace. It was generally agreed that the changes that would be needed would benefit all employees.

**Mindful management.** Good management was seen to be essential to successful job placement. The importance of good management skills and practices was highlighted as a necessary workplace adjustment that would ultimately benefit all employees. Need was expressed for managers to be selected on the basis of their ability to look after staff and to be appropriately trained to treat staff properly. Key components were perceived to be: a relationship of understanding and trust between employer and employee; good communication; regular availability of coaching and mentoring support for both employees and co-workers; ability to identify and respond appropriately to triggers; and mutually agreed contingency plans. In terms of communication, it was

considered important that managers be approachable for purposes of discussing any support needs and providing feedback if required. One respondent highlighted the important role that workplace support could play in early detection and intervention in the event of relapse.

Employer attitudes, qualities and attitudes were considered significant variables influencing the level of employment support. A family member considered that “for an organisation to take on an employee with schizophrenia [it] would need to be an exceptional type of person with an exceptional type of environment because the needs aren’t the same...tolerance, understanding, respect and compassion.” A medical practitioner felt what is needed is employers “...that understand that they have the illness. They’re allowed to be unwell but come back to work [when they recover]” even after extended periods of absence that may be required following an episode.

**Workplace adjustments.** The most common needs expressed in this area were competent managers and supervisors, flexible work options, training and supervision, coaching or mentoring. The main workplace adjustments were a supportive work environment and flexible work options.

It was clear from responses that individuals vary in terms of their need and tolerance for particular types of social interaction and work schedule. It was suggested that there is a need for willingness on the part of employers to consider what roles might be best suited to the employee and accommodate workers in roles that are suited to their abilities and interests, as well as their ability to cope with social interaction and stress. Participants referred to the following workplace adjustments that may be required:

flexibility of working hours, especially in the initial stages following a period of treatment; willingness to schedule work around doctor's appointments; willingness to adapt tasks around needs of the employee during episodic fluctuations of condition; flexibility to re-assign work tasks if necessary due to episodic fluctuations in condition; willingness to continue to employ a person even if they have long periods of ill health that prevent them from working.

There were individual differences in what was seen to be an ideal physical work environment for a particular individual. One client respondent expressed a particular need for a safe working environment. However, the consistent need was for a workplace with a positive and supportive *emotional* environment. The need for a supportive work environment that reduces work-related pressure and stress was perceived as a need for all workers. Employee assistance programs in larger companies were viewed as a positive workplace support measure and a subsidy was suggested for employers to introduce these programs. A client participant mentioned that he had made good use of a respite facility or respite room at the university at times and found this helpful. Others recommended that a "sensory retreat room" or "chill-out room" would be a popular feature for all staff members. The provision of meals and affordable social networking opportunities that offer opportunity for recreation and relaxation were other suggested workplace enhancements. Respondents highlighted the importance of the emotional climate of the workplace and identified the need for tolerance, respect, understanding and compassion. Words used to describe the preferred emotional climate were acceptance, tolerance, respect, understanding, flexibility. A family member of a person with schizophrenia

considered that "...having people around him understand him would be essential for his survival in that kind of environment [work environment] I suppose. It's a supportive environment thing." This respondent also commented:

...it would be more of his wellbeing than anything that would need to be taken care of, rather than the workplace health and safety. It would be his wellbeing that would need to be nurtured and supported...than anything else. (Family member)

**Co-worker support.** There were multiple references to the need for a supportive work environment in which an employee has the "right" or "willing" workmates. Particularly for those severely affected by psychotic experiences, it was seen as essential to their viability in the workplace to have co-workers who are aware and understand the situation. Businesses that affirmatively provide employment opportunities for people with mental health conditions were seen to be more conducive to supportive employer and co-worker relationships. Collegial relationships with co-workers were seen to be an important factor in motivating people to attend work. Client participants expressed the importance of being able to de-brief with understanding and supportive colleagues. High functioning participants were aware of the importance of supportive collegial relationships and were making conscious efforts to build networks of supportive relationships at work. For those without family support, a buddy system was suggested whereby a trusted colleague or supervisor could provide support and facilitate work adjustments as necessary to prevent escalation of difficulties. Co-workers were also seen to play an important role in early identification of coping difficulties, provision of informal support and alerting management to the need for more support.



Co-workers expressed a need, subject to confidentiality requirements, to be briefed about the situation and advised of any workplace health and safety issues. In order to provide support, it was felt that co-workers would need education to be aware and know how to cope with the situation. Due to the invisible nature of the condition, an employee would need to be willing to disclose the condition and give consent to inform and educate co-workers.

There was evidence from the sample that co-workers can and do develop supportive relationships with employees living with psychosis. Participants provided examples of work situations where co-workers have been made aware and have developed supportive relationships. The nature of relationships with co-workers appeared to vary along a continuum from completely autonomous, where co-workers showed “a lot of faith” in the employee, to the other end of the continuum, where the co-worker assumed the role of mentor and carer. It was also suggested that work relationships could potentially develop into supportive personal relationships.

### **Improving Self-Management Skills**

There were several references to the need for a client to take personal responsibility and play an active role in their own treatment and self-care. A number of respondents emphasised the importance of a proactive approach to management of the condition rather than being a passive recipient of treatment:

...you have to have a positive attitude. I know a lot of bipolar people would rather just sit there and say, “Ah f... it. It’s the doctor’s problem. They’re the ones that made me this way”...realistically no, no one’s to blame but you *are* to blame if

you don't get off your arse and help yourself.....and you don't go see a doctor and try and sort out medication...and if that doctor is not working for you shit go find another one. There's plenty out there and they're all there to help. It's taken me ten, fifteen years to find the right doctor. Now I have I'm not letting them go.

(Client with bipolar disorder)

A therapist also talked about the importance of personal responsibility in relapse prevention:

... you must take responsibility for yourself and for your own management of your situation and this is where, you know, it starts with that step, them [being] willing to take responsibility and with support and encouragement be able to go on, but if they're not ready for that it doesn't matter how much support you can give them. (Therapist)

Personal responsibility includes seeking out appropriate treatments and proactively accessing supports. It was recognised that much hard work is required on the part of the client to build the foundational skills and routines required to manage the condition to the point of being able to function effectively on a day-to-day basis and maintain work. Self-management issues referred to by participants included personal relationship with the condition, medication, self-awareness and self-regulation.

**Relationship with condition.** The importance of people managing their relationship with the condition was emphasised by a number of participants. Respondents felt that successful self-management involved moving away from feeling like a victim of

the condition, to assuming a position of active self-management. A peer support worker commented:

The goal of recovery, to me, is to actually take that mental illness and what we say is put it on a leash (laughs) and put it in the background. It's in the background of your life rather than having it as your identity, which happens to a lot of people, that it's in the forefront of their mind, their lives and it's like their whole identity is schizophrenia or bipolar. To me, recovery is when you make that [the condition] smaller and smaller and smaller till....like honestly I forget about it, all the time, that I even had a mental illness even though I've had in the past, you know, very serious...four or five major episodes and admissions. It's like it goes completely away and you're so busy living your life that you forget that you even have a mental illness.

People who were effectively managing their condition felt that the aim should be to place less focus on the condition and for it to become a less prominent aspect of one's life:

....when I go home I don't...never even think about it. It's not something that's talked about. It's not, it's just like....it would be like if someone has haemorrhoids let's just concentrate on our haemorrhoids all the time. Like, you know, I want to concentrate on the good things and the important things in my life. (Peer support worker)

The same participant also said that the condition should not be allowed to get in the way of living:

...so that expectation, that having a mental illness is *no reason to stop living*, is a big thing I think. The thought never crossed my mind that having a mental illness would actually make you disabled in any way. (Peer support worker)

**Medication.** Most participants endorsed the need for medication. There was a wide-spread perception that compliance with medication is a key to ability to sustain work. A client with bipolar disorder asserted: "...medication's really important. It's the key. Yeah. You have to be on medication." She explained further, "I have a disability, yes, but the way that it impacts on me is not all that great now, considering I've got the meds and everything like that." Several participants also referred to the need to find a good general practitioner, to ensure that their medication regime is optimal and to comply with prescribed treatment.

**Self-awareness.** Respondents talked about the need to improve self-awareness, self-acceptance, self-care and self-regulation. Self-awareness needs identified by participants included awareness of personal interests, strengths and limitations, impacts of the condition in an employment situation, recognising triggers and signs of becoming unwell. It also included references to awareness of the need for self-care, self-acceptance and self-regulation in terms of the type of work undertaken, working hours, contingency plans and appropriate timing of return to work.

**Self-management strategies.** Participants spoke of the need for and use of cognitive and behavioural strategies to manage the condition and cope with workplace challenges. Client respondents who were accessing treatment from a psychologist reported that they found this form of treatment helpful in developing strategies to cope at

work. This includes developing more knowledge and understanding of the condition, establishment of healthy routines and life-style and strategies to manage emotions and behaviour including interpersonal skills and stress management skills. Figure 49 shows references to self-management needs.

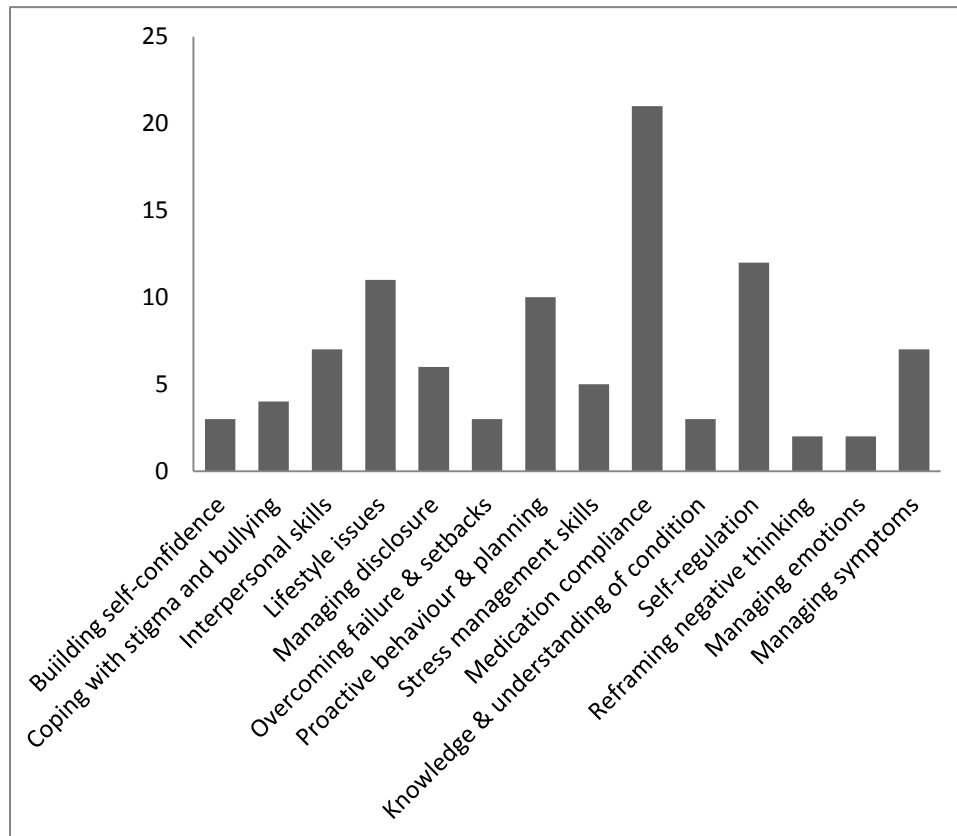


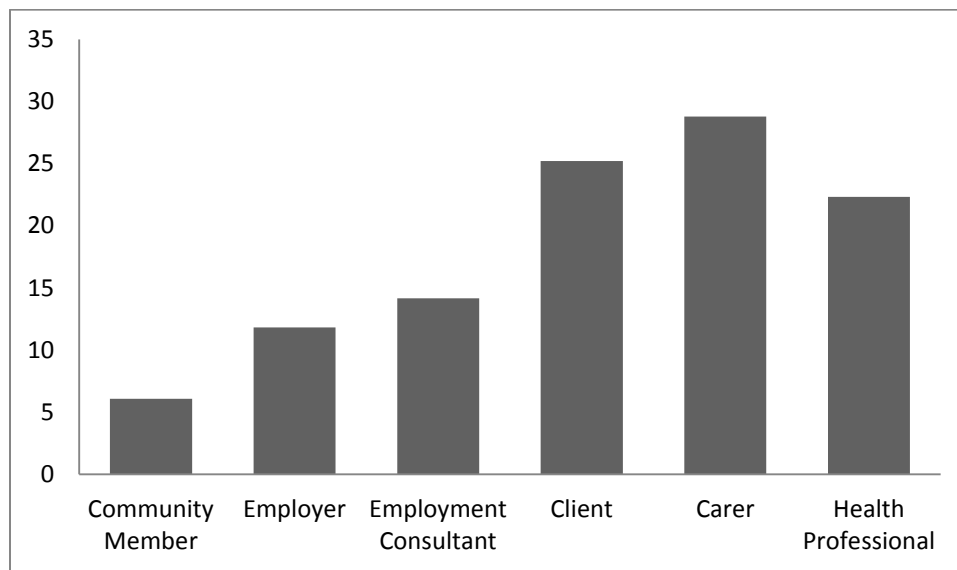
Figure 49. Number of references made to each of the identified self-management needs.

**Home care and support needs.** Family and friends were attributed with providing practical support with work arrangements, career guidance and a positive career role model. A carer questioned the appropriateness of the term “unsupported employment” in the context of people living with a serious mental health condition. She compared the extensive background support required at home, particularly in the early

stages of the condition, to the support needs of an elite athlete, and expressed anger that the essential work-related support provided for the jobseeker at home by the carer usually goes unrecognised.

### Summary of Employment Assistance Needs

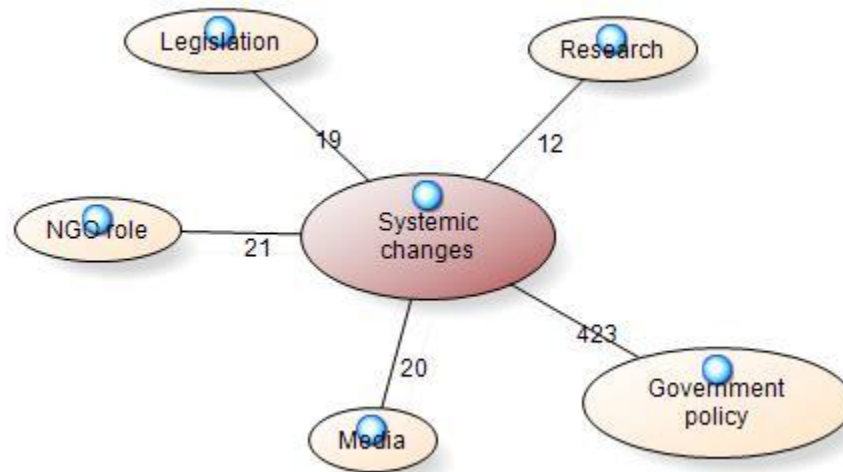
The most frequently referenced employment assistance needs were in the areas of employment services (366 references), workplace support (247 references), self-management skills (172 references), employment support personnel (82 references) and employer needs (78 references). The most commonly referenced employment service need was for job-seeking assistance (130 references). The total number of coding references to employment assistance needs according to stakeholder group is shown in Figure 50.



*Figure 50.* Average number of coding references to employment assistance needs according to stakeholder group.

### Chapter 13: Systemic Changes

This final results chapter focuses on participant references to the need for broader systemic changes. Systemic changes include social and government action to address ignorance and inequality and promote sustainable employment for people living with psychosis. It includes references to government policy, legislation, the media, the role of non-government organisations and research. As can be seen from Figure 51, changes in government policy were the most frequently referenced systemic support need.



*Figure 51.* Summary of systemic support needs. The numbers entered adjacent to connector lines represent the number of participant references, or coding density, for each of the main barrier nodes.

A more detailed analysis of systemic change as an employment support need for people living with psychosis is provided in Figure 52. This chapter will focus on description of the contents of the most heavily populated nodes.

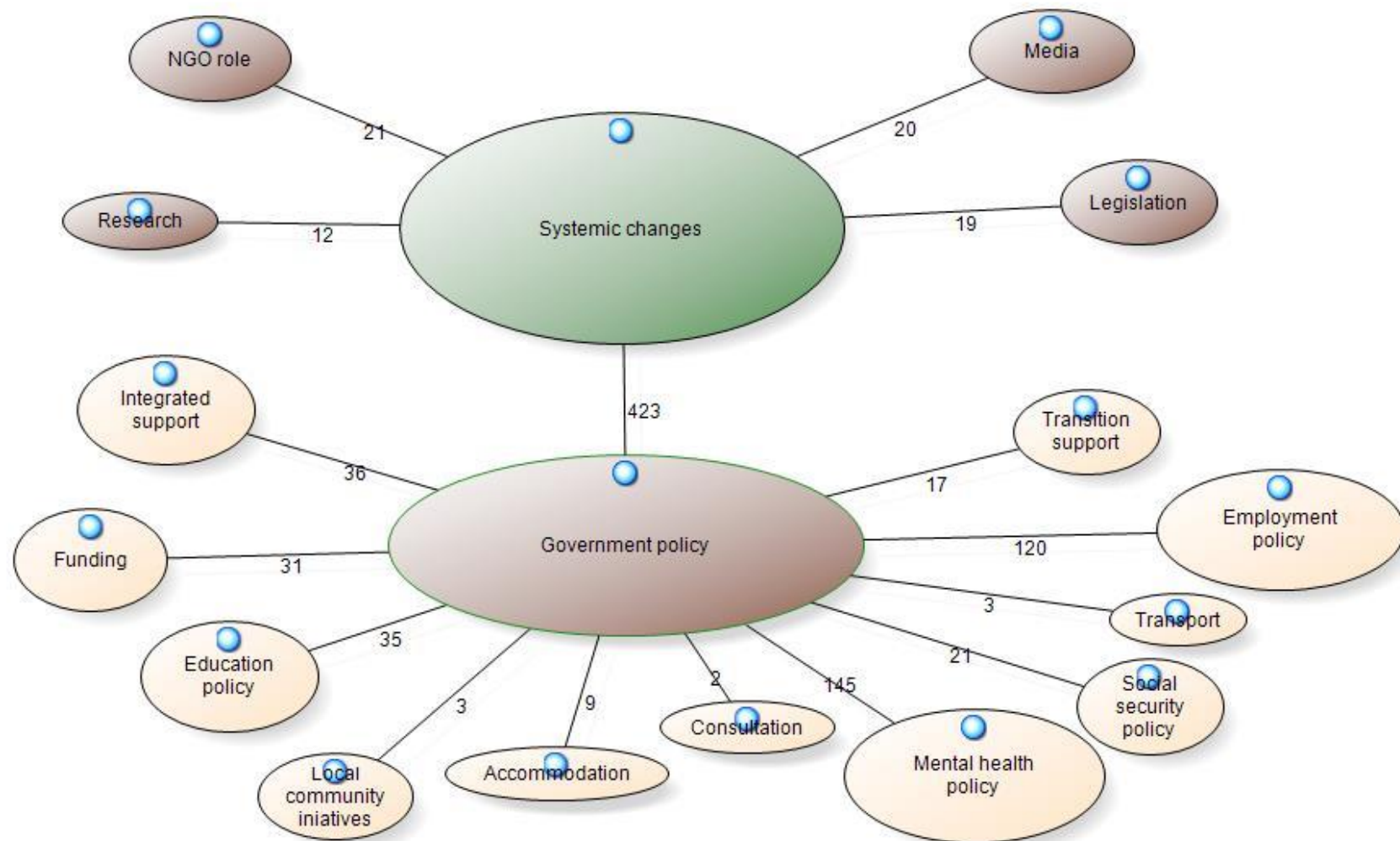


Figure 52. Second order analysis of systemic changes.



Participants expressed the need for change across a broad range of areas. Not all participants could foresee a time when employment prospects would be much better for people living with a mental health condition. One health professional, projecting into the future, believed circumstances could actually become *more* difficult for people living with psychotic conditions, depending on the views of society and government at the time.

### **Government Policy Changes**

Government policy changes were the most frequently referenced systemic support need. The areas of government policy most frequently cited were mental health, employment, education, social security and the need for integrated support.

There was a call for an educated government that allocates funding appropriately to ensure access to services and support. Carers expressed need for improved allocation of government funding for mental health. There was a need expressed for more consultation between policy makers and the people affected by policy decisions. A carer commented that too much money is spent on psychiatry services while more support is needed in the community:

The money that's been poured down and thrown down and flushed down the drain is billions of dollars that could be put into a much more constructive [expenditure of government funding] ....give it to the carers they'll work it out...(Carer)

**Mental health policy.** In regard to mental health care, the need was expressed for a new paradigm of care which is less reactive and more proactive with the aim being to integrate the person back into the community and prevent relapse. Access to mental

health services, effective treatment and a recovery-oriented service received prominent attention. The most frequently referenced needs in relation to mental health services were for services to have a recovery orientation, improved treatment services and access to community support services.

***Recovery orientation.*** Participants suggested that the focus of treatment should change from behaviour management towards a focus on recovery. This would require a change from a reactive approach using the “medical model” for treating problems, to a more proactive focus on recovery and re-integration into the community:

...you would hope as well if we were in that future point that it wouldn't be such a reactive area of care...it would be perhaps a bit more proactive in terms of caring for someone and then integrating them back into the community, as opposed to just caring for them in isolation and out of the community.”

(Community member)

Many respondents referred to the need for services to focus not simply on alleviation of symptoms but on assisting the person to recover in the sense of living a meaningful life. It was suggested that a recovery approach should extend beyond treatment and sorting out problems. A carer advocated for a more proactive approach to health care in which assistance goes beyond merely sorting out problems to a focus on "flourishing".

Carers felt that the process of recovery should ideally start from commencement of treatment, with early recognition of needs and a recovery plan and structured pathway

provided from day one of diagnosis. Carers felt proactive planning needs to occur from the time of diagnosis in order to provide hope and a pathway to recovery:

P84: You have a little package straight up front. This is what we need to do to get you back on track and to get you back out into the lifestyle, and there is light at the end of the tunnel. It's not like, "Sorry about that mate, there's no hope, you'll have this forever and, you know, see you later." (Laughs)

P85: Sorry about that. Next, next... (Carer)

In particular, the need to maintain self-confidence and cognitive skills was deemed critical to the long term outcome. It was considered that the level of recovery should envision joining or returning to the workforce. There was also emphasis on recovery as a collaborative process in which the patient's opinion is central to important decisions regarding their care, including their ability to cope with perceived stressors such as work or study. A psychiatrist suggested clinicians should "follow the lead" of the individual patient in regard to their capacity to cope with work-related stress, commenting, "....if you're working from the patient's point of view, then it's fine because the patient leads you..."

It was also felt that recovery planning should extend to provision of back-up plans for employers and others close to the person to assist them with provision of sustainable employment. Clinicians were in agreement that more active involvement of health providers in managing the transition to work would reduce the risk of inappropriate placements or bad outcomes that could occur if the client self-initiates the process without adequate support.

It was suggested that employment should form an integral part of a recovery plan and that time needs to be spent on planning future work goals and a career pathway, and that an important aspect of case management would be attention to life skills and pre-vocational support needs. There was a call for a move away from stereotyped approaches which emphasise limitations, to a focus on potential, what *is* possible, and what the client feels they need to improve their quality of life. This would require a more collaborative approach between case managers and other stakeholders involved in the person's recovery. It was felt that this would also facilitate valuable feedback to clinical staff on how *patients* function in non-clinical settings, and provide needed perspective to counteract the effects of the "clinician's illusion" as well as inform the approach to care.

Responses suggested a need to revisit role descriptions for mental health staff in order to change the focus from compliance to a more positive focus on recovery. This would require review of role descriptions of health professionals to include a more positive focus on goals, values, likes, dislikes and hobbies. In expressing their understanding of the concept of recovery, participants emphasised the need to work collaboratively with the client in planning goals congruent with the client's values and aspirations.

In contrast to the cautious and laissez-faire approach towards work adopted by many health professionals, peer consultants talked about recovery as a process of measured risk-taking and felt there was a need to adopt a tough-love approach to work and push people to achieve more as they often lack confidence. This sentiment was also expressed by a carer who felt that it was better for clients' self-confidence for them to be

supported to overcome obstacles rather than lowering expectations. The recovery orientation was variously described as “returning to your life” and “pushing oneself to take risks”.

Rather than the hospital being the main focus of treatment, it was felt that decentralisation of services should occur with focus on reintegrating the person into the community including employment. Carers argued it would be more cost-effective than hospitalisation to provide more supports in the community. Needs that were identified were for supported accommodation, basic living skills, and support to re-integrate into the community and improve their quality of life.

...to me the key area is putting that link between when they finish their hospital treatment and then they're thrown out into the [community]...there needs to be... a graduated introduction back into the community... (Employer)

One participant suggested that every mental health team should have a consumer worker in it and that consumers should be involved in recruitment processes for mental health staff. Peer support workers were seen to have capacity to both identify and build effective rapport with people experiencing mental distress, due to their willingness to disclose their own experiences of mental health problems. Peer support workers were seen to play a role in building self-esteem, which was deemed conducive to a person approaching employment. A peer support worker explained: “I talk to them as one human being to another, not as somebody that's got a label on them, and that builds their confidence, and by building confidence I think you can then direct people into the employment sector”.

Participants talked about the need for support programs to emphasise engagement, motivation, participation and self-empowerment. Employment, whether paid or unpaid, was perceived as “absolutely, well and truly within the recovery model”. This is evident in the following comments:

...education of the public health system [is needed] to encourage people back into the workforce. There's a deep deal of discrimination against supporting people who want to get back to work and I think a lot of that can be overcome. (Client with schizophrenia)

With hospital admissions, whether they be public or private, for a mental health patient, maybe there should be an employment review as part of that, just to say what were you doing, what are you doing... (Client with schizoaffective disorder)

I think most of them should be employed soon after they've been considered to have recovered enough and...I don't think that should be...very late after they come out [of hospital]. I think they should have some work to go to... (Client with schizophrenia)

Participants also referred to the need for focus on improved self-management of conditions including deeper understanding of the condition as well as improved self-awareness and self-regulation.

***Treatment needs and quality.*** The importance of finding a supportive G.P. who understands the condition was mentioned by a number of participants. There was a need

expressed for more emotional support and a more optimistic and open approach on the part of psychiatrists.

P52: And I think it would be great if psychiatrists could offer more emotional support to the people they're trying to help. You know just give them *hope*...say kind things and have a rosy picture of the situation and that would help people...whereas they come out of it with a pretty grim picture. Yes, I think psychiatrists being more supportive and more positive would really help. (Client with psychiatric disability)

P56: And tell you what they're thinking and put their cards on the table instead of not telling you any of the side-effects or anything like that (Client with schizophrenia)

Most participants acknowledged the importance of medication in effective treatment:

...if you're on a proper medication you can handle things a lot better but if the doctor hasn't got your medication right, which has happened for me for quite a few years, you've got no chance (laughs)...medication is the key. You've really got to get the medication correct". (Client with bipolar disorder)

Some client participants, however, felt that medication should be a choice due to the adverse impacts and side-effects of medication on ability to work:

...there seems to be enormous pressure on doctors to keep patients permanently medicated. I think if you were given a chance to be very lightly or unmedicated you'd have much more chance of working. You spend a lot of time coping with the side-effects. (Client with schizophrenia)

So maybe the mental health system itself needs to take some responsibility for the employment prospects of consumers. They need to be taking responsibility saying, “Well, we’re not going to medicate this person too much cause they wanna work”. So that department, the mental health system, has to start taking some responsibility too for our employment. (Client with schizophrenia)

It was felt that the mental health system should assume more responsibility for ensuring that people who want to work are not *over*-medicated. Participants pointed out that medication needs to be adjusted so as to not interfere with employment prospects and allow people to participate in work roles. Participants referred to the risk of relapse associated with changes in medication regime and the need for careful monitoring of impacts of changes in medication in order to avoid loss of employment. A psychiatrist explained: “...if you have somebody with epilepsy, for example, they might not disclose...and if they then go through a medication change they’d probably go on sick leave to do that”.

Several participants commented on the need for scientific advancement to eliminate the problem or improve the effectiveness and reduce side-effects of medication. An employer commented, “It might depend on better medication some time down the track, so people don’t appear as though they’re slow and stupid”. It was also felt there was a need to extend treatment beyond medication to include interventions to support people to find a sense of self, improve self-confidence and empower them to rebuild their lives.



There was a call for improved access to case management and counselling support.

I think any psychological problem shouldn't be just medicated... 'cause your mind is your mind. I think medication makes your mind weaker if anything... if you keep medicating them all the time, just give it to them, they wouldn't ever have that [awareness]. It wouldn't ever evolve from there. (Community member)

I think a lot of the time the medication can become a walking stick or a band aid. And a lot of the time these people can learn to accept the diagnoses, and to live with it, so to accept okay so I'm hearing voices. I don't have to do what they tell me. I can just laugh it off. Yes, I might hear somebody going la, la, la to me all day but it doesn't mean to say I have to act on it. I think if people just take medication all the time it doesn't let them build up the strength to have that argument within themselves. It just goes "Oh God, I'm hearing voices. I'd better pop a pill". So they don't learn the necessary skills to deal with the symptoms.

They rather just band aid the symptoms. (Psychologist)

A psychiatrist acknowledged the need for psychiatric treatment to go further and incorporate consideration of employment.

I think we are so busy with the earlier stages of getting the person moved forward...because employment really is the final stage. I think a lot of us don't reach that stage. I think we as a group don't have high expectations of our patients in terms of employment. If the voices are gone, the person's euthymic, if he's on

disability and is reasonably content, we're content...and yet the true contentment from them would be if they get employed... (Psychiatrist)

Treating doctors play a key role in encouraging patients to work. One respondent considered that her general practitioner had played a pivot role in her successful career:

I remember going to see my doctor and he said, "Well, I'm not going to write another letter of referral. You need to go back to work" and I was so anxious about this, and he said, "You just need to start with one day [name]", you know.'Cause I had a business prior to becoming unwell and just had lost all my confidence and threw my business away and he said, "Just *one* day"....I often think about that and think, well, if my doctor had continued [writing letters] for me, my life may have been very different and I mightn't be sitting here today but that must have been something that he saw in me....

A psychologist, describing a man with chronic schizophrenia who successfully undertook charity work, highlighted the power of recommendations made by a doctor:

...his doctor had told him "You should give charity work a go". I think that was key too: the medical professional saying, "You can work". You know people will just give up all their power to a doctor and the doctor knows everything and, if the doctor says you can work, people will put a heap of pressure on themselves to do it...do what the doctor says. So the doctor had said "I think you can do charity work" so he shows up, "I think I can do charity work". (laughs)

An occupational therapist felt that work should be acknowledged as a health outcome and more funding allocated to health services to facilitate employment

outcomes. It was felt that funding should be allocated to clinical services for a body of work that needs to be done in job preparation or retention, and for collaboration with other agencies to achieve common goals. There was a call to increase the level of occupational therapy services, and in particular the maintenance and rehabilitation of cognitive skills from the earliest possible stage in the treatment process. There was support for more ready access to cognitive assessment and retaining programs. Computer-delivered programs were seen as an ideal and economical way of providing this training.

A psychiatrist referred to the importance of maintaining wellness and of flexible and rapid response to early warning signs of relapse. A psychologist indicated that even people who are established in employment need access to regular ongoing psychological and psychiatric support to manage their condition in order to maintain employment. There was, however, some uncertainty expressed about whether people with these conditions are, in fact, eligible to access psychological treatment through Medicare.

***Access to mental health support services.*** A more community-based model of care was proposed in which more services would be delivered in the community rather than being hospital-based. Carers expressed cynicism about the amount of funding allocated to psychiatry services and felt it would be more cost-effective to improve community mental health services. Carers felt that more money should be allocated to support people with psychiatric disabilities living in the community.

It was felt there needs to be more attention to meeting the home and community care needs of people living with psychosis along the lines of services provided for aged

care and physical disabilities. A major need was expressed for secure housing, support to maintain stable accommodation, supervised accommodation and half-way houses for people discharged from hospital following a psychotic episode. The need for improved transport options was also discussed, including pick-up buses. The extent of a person's support network was considered an important factor in successful return to employment following a relapse. Support workers such as peer support workers, mentors and social workers were perceived to be a valuable source of practical support with activities of daily living and community access, as well as potentially playing a valuable role in re-engaging people with the employment system and supporting the transition to work. It was felt that if clients receive adequate support from health and social services in the community, employment consultants can concentrate more time on achieving employment outcomes.

The general practitioner and psychologist were seen as important sources of government support in the community. Participants perceived a need to remove barriers to eligibility for services and for improved access to counselling and psychological services both in the community and through expansion of employee support programs. As one community member said: "...they have mental health plans and things like that but they only last for a certain period of time and then they have to start paying for it themselves. You know, so better access to things like that".

Participants suggested more funding is needed to enable mental health services and private psychologists to provide interventions specifically aimed at re-engaging people with work. It was also felt that private psychologists could be funded to play a

more active role in supporting employment services to achieve outcomes among people living with more severe and persisting mental health conditions. An employment consultant referred to the need for after-hours specialist mental health services:

So in an ideal society people like ourselves [employment consultants] wouldn't be worked to the bone to try and support all these people (laughter). They'd have the specialist support provided for them and it doesn't just work nine to five on a Monday to Friday basis.

Participants perceived a need for more access to personalised and practical support. Support groups were seen to be a valuable means of overcoming social isolation and improving self-management skills. It was suggested that support groups provide opportunity for clients to benefit from the non-judgmental attitude and understanding of other clients. Support groups were also perceived to have value as a means to restore a sense of self and build the self-confidence required to access supports and participate in employment. One participant with bipolar disorder even seemed to derive some therapeutic benefit from attending the research focus group: "Coming to things like this [research focus group] is helpful because you see that other people talk about it as well...and talking about it kind of helps a lot". It was apparent that some highly valued services are provided without personal remuneration such as a bipolar disorder support group run on a voluntary basis by a registered nurse:

... he needs to be given an award for starting that and for the time he dedicates to doing that on his own recognisance...he doesn't get paid. That support group has been very good...he gives an eight week, ten week course or twelve week course

once a week on the learning, coping skills of being bipolar. (Client with bipolar disorder)

The need for free mobile calls to employee support help lines was suggested by this participant:

And what I found difficult in that scenario was at home I only had the mobile phone. I didn't have a landline. So when I was away for that time off work I didn't have any interaction with anyone really and it would have been nice to have been able to pick up a phone and not actually cost a fortune. (Client with schizoaffective disorder)

A need was expressed for people to be assisted to access support services, including employment support services *before* they leave hospital as they may lack the initiative or self-confidence to do so once they are discharged. Making employment-related services easily accessible within clinical services was seen as a positive measure.

***More support for carers.*** One carer likened the support needs of people living with psychosis, particularly in the early stages, to those of an elite athlete. She described the practical support and encouragement needed to successfully support her son back into employment and overcome obstacles.

There was recognition by participants that psychotic conditions are “hard to live with”, and some parents were perceived to be “at wits end” trying to cope. There was also recognition that family breakdown and lack of family support often leads to a deteriorating spiral of homelessness and mental deterioration. Carer participants voiced a need for more emotional support for carers to safeguard their own mental and physical

health and relationships. The need was expressed for more opportunities for mutual support for carers, including opportunities to socialise and access respite care to enable them to go on a holiday. Integration of their careers into work roles was seen to allow some degree of sharing of the burden of care. An employer observed that: “the other staff, because they’re aware of it, they’ve ended up being like mentors and carers for him so as a group they work well together.” Another employer referred to the expressions of gratitude received from parents, who were described as “just thanking us continually for our support.”

**Employment policy.** There was a call for a change of focus from classifying people based on deficits to identifying strengths and motivating people with lived experience of psychosis to maximise their potential.

I think there needs to be a whole shake-up of the whole employment system to move away from the looking at a diagnosis and putting someone into a category to looking at ability and focussing on enhancing those capabilities. I think at the moment it’s the other way. It’s look at a diagnosis, put ‘em in a box. (Former job capacity assessor)

The most commonly cited aspects of employment policy were employer incentives, employment service providers and job opportunities.

**Employer incentives.** Suggested changes in employment policy focussed heavily on financial incentives to mitigate the perceived risk to businesses of employing people living with psychotic conditions. Employer incentives were seen as a means to off-set potential risks to the business; promote retention of staff who may be experiencing

difficulties; and encourage employers to gain first-hand experience employing job seekers with psychosis so as to discover their value as employees. There was a perceived need to compensate employers for periods of reduced productivity; need to employ additional staff during episodic absences from work; provide additional paid leave if needed; and adjustment periods for people who may realistically be less productive due to the effects of long term unemployment. It was felt that a financial incentive would make employers more willing to accept the perceived business risks attached to employing a person with a serious mental health condition:

I guess also if the government were willing to fund or give small payments to the business to cater for if the worker needs an extra week off paid leave...If they can financially cover that then small businesses would be more willing to take the risk initially. (Community member)

P12: But then if someone's going to help them out with a job well then the government system should support that employer

P8: There is a risk associated with employing them I guess so there's got to be an incentive I would think. I would feel like I would need an incentive to do it, to be honest, to overcome the risk. (Community members)

A client with bipolar disorder suggested "...some sort of education for employers and some sort of help for them as well because it's not like having a normal full-time employee. Like it's a little bit choppy (laughs)...yeah...sometimes." The same client



suggested that “an extra few days’ sick pay a year subsidised by the government would be helpful.”

Traineeships for people with mental health issues were suggested as a possible form of government funding incentive for employers. Subsidised traineeships were one possible means to compensate employers for the additional coaching and planning that may be required. Financial subsidies were proposed to assist employers with the cost of implementing training programs in mental health awareness for management and employees. A businessman suggested the government should, in consultation with the appropriate people, set up training programs in mental health awareness, and compensate employers for the costs associated with delivery of these programs to manager and employees. Subsidies were also suggested to enable companies to make employee support programs available for their staff.

Whilst some participants seemed to endorse initial incentive payments to employers or short-term wage subsidies, others expressed concerns about the possibility of early termination of employment when the subsidy ends, and felt that a system of longer term incentives was needed.

...our biggest expenses are wages, so I think a wage subsidy would be the way to go...as long as you didn't then have people taking advantage of workers because that's always the problem...could be a problem. It's always a risk you take I suppose that once the incentive's gone, the employee goes...but if it was long-term that would be even better but I'm not sure if the government would do it long-term. (Employer)

Tax concessions were suggested as a form of employer incentive:

Well, from a business point of view, if I was to go and employ someone with a mental disability over somebody without a mental disability, there'd have to be something in it for me. I'd want something like a tax break or some incentive for the company. What's in it for a small Australian business to take on board these liabilities? So you know I think something like tax breaks would be fantastic.

(Small business owner)

Various forms of government wage supplementation scheme were also suggested to enable employers to employ people who have reduced productivity at award wages.

And it occurs to me that, okay, if government is going to pay a pension, why not say give that pension to employers as a wage subsidy for three years or whatever it takes to get people to take them on. Industry will do it if they have the incentive, that's how I see it. (Community member)

One respondent, however, pointed out possible misuse by employers of incentives:

"...one of the dangers I would see, sometimes, of subsidies is that you take someone on because you're getting a financial subsidy and you give them a broom and put 'em out to sweep the gutter." One employer, who was unaware of the supported wage scheme, strongly objected to the principle that an employer could legally employ *anyone* at below award wages. One manager proposed an alternative to the supported wage scheme whereby the government pays the gap for any productivity deficit "so the person is not discriminated against by getting a lesser salary for doing the best they can." He recommended that employees who are assessed as being eligible for a supported wage

should be paid *at award wages* and that the balance of wage required to off-set any productivity deficit be paid to the employer by the government. This suggestion was subsequently endorsed by other participants in the study. A businessman felt that the subsidy should be reviewed at regular intervals and extend long enough to allow the person to be assimilated into the workforce:

...every individual's different and every job's going to be different so you can't say the subsidy will be six months full stop. It should be geared up to an assessment scheme where those people are professionally assessed and the management, their immediate supervisor and possibly the next manager up, puts in their report. It needs to be both qualitative and qualitative so it's got to have open-ended questions so you can write what you really think. It would be an assessment scheme so for some people who assimilate very quickly it might be three or four months. For others who may have a little more difficulty, it might be twelve to fifteen months. It needs to be an independent agency with the psychological skills to look at these things...so you've got a psychological angle looking at it and you've a business angle. At some point in time, and that would need to be worked out, they'd say this person no longer needs to be revised and at that point the support would be cut off because the person would be self-supporting within the corporation for want of a better word. (Businessman)

Another proposal was an insurance scheme to overcome employer concerns about the risk of liability associated with employing a person with a mental health condition. However, an insurance was seen to potentially have "loopholes" and be subject to abuse.

Subsidies were proposed to promote business enterprises in which owners and/or employees have lived experience of psychosis. Several respondents emphasised, however, that all businesses employing people with psychosis should remunerate them at or above award wages.

***Expanding job opportunities.*** Participants identified a need for the government to engage employers to raise awareness of issues relating to the employment of people living with psychosis, and the benefits of employing this cohort of workers:

...maybe the government can put on like seminars for employers just on like hiring people with mental disabilities and things like risks and advantages because I went to an information session a few weeks ago and they mentioned that often people with mental disabilities actually keep a job for longer. They're actually more committed, have less sick days and things like that. So if you tell that to employers they might be more willing to hire people. (Community member)

The need was also expressed for government to show leadership in its own employment practices. A number of participants felt the government should lead by example in the employment of people with severe mental health conditions:

P 72: ...I've been to quite a few conferences where they [government representatives] talk about how they are going to start employing people with mental health or disabilities but you don't see them working in our own government. You don't see them working in the state offices and things. You just don't see them and I think that's part of that education is wave that magic wand over them and say, "Start showing us, start showing society..."

P75: Lead by example

P72: ... that you walk the walk instead of talking about it.” They made a policy at one of the conferences I went to that I think they were going to try and get like three percent of disabled workers or people with mental health issues but I still haven’t personally come across, from my personal experience of trying to find employment for these people, I still don’t see those vacancies. I’d don’t see them, even internally, saying we are trying to look for these type of workers.

(Employment consultants)

Another social worker commented:

It occurs to me that perhaps government has to take the lead if we’re looking for potential employers. If government could do some sort of research on people working for them and then could go to the marketplace and say we have X percent of people with mental health issues and their attendance rate is ninety nine percent and it would at least be a starting point... (Social worker)

Some suggested that the government should also target large business. It was argued that larger firms have more potential to offer a wider range of suitable employment options and were better positioned to accommodate unplanned absences. It was also pointed out that some larger private companies choose to employ people with disabilities as a means to promote their corporate image in the community.

So you’d do it, in my view, by encouraging the large corporations, and once the large corporations are doing it, there’s a bit of a trickling down effect to the middle size businesses. I don’t think it’ll ever get to the small business because

they just can't afford to do thing like that...they might be able to, I don't know, but you've got to do it by convincing them that it's a worthwhile thing to do, that it's not going to cost them any money, that there's gonna [sic] be minimal, if any, risk involved and it can add to, you know, their workforce being a stable workforce. (Businessman)

It was also proposed that all employers should employ a quota of staff with disabilities as the default option and receive appropriate funding and provide supports to do so. Not all participants were in agreement with a quota system, however, with one participant commenting that while companies are still identifying people for purposes of meeting a quota, "it's not going anywhere" and that people should be integrated into the workforce because of their skills, without making an issue of disability.

An employment service provider indicated the supported wage scheme is commonly used as a means to increase employment opportunities for jobseekers with chronic mental health conditions. However, a businessman protested that it is morally wrong to employ *anyone* at below award wages and suggested government subsidies should be payable to enable employers to employ anyone at award wages.

There was widespread support for the expansion of social firms. Several respondents suggested that government or large corporate organisations subsidise the creation of competitive businesses which are owned or operated by a staff that includes people living with mental health conditions who are paid at award wages (see also page 305).

***Enhanced employment service provision.*** Opinion seemed to be divided on the need for specialised employment services for jobseekers living with severe and persisting mental health conditions. Some participants proposed that more funding be put into specialist services to assist jobseekers with mental health issues into employment and felt that trained consultants may achieve better outcomes than a service that is required to deal with a wide range of other disabilities. While some felt there was value in specialist employment services which catered specifically for jobseekers with mental health conditions, this view was not endorsed by all participants. Some suggested that in the future all employment services should be mainstream services, with the skills to cater for the needs of people with mental health conditions.

I think you'd probably reduce stigma if you had just all mainstream but you would have to do a lot more educating of everyone in mainstream services to really lift their level of education about mental illness, about recovery. (Peer support worker)

Some felt that specialist employment services for people with mental health conditions reinforces stigma by placing focus on *disability* and that ideally in an integrated society all job agencies should be mainstream services and have the specialist knowledge and capacity to effectively service the needs of *all* jobseekers including those diagnosed with psychotic conditions:

...in an ideal world, I suppose that education and acceptance becomes so great that it eliminates, or at least lessens, the need for services like ours. So basically

...I'd be out of work. So maybe that's a vision. (Disability employment consultant)

A community member predicted that due to historical segregation there may be some reluctance to integrate mainstream and disability employment services:

I just think there may be a hesitancy for people to do that [integrate employment services] and perhaps that's just historic; it's just because we've always kept it separate (laughs)...but you know...mental health's always been over here and the rest of us are over there (laughs)... (Politician)

Others expressed concern that if all jobseekers were mainstreamed, those with mental health problems would be “swallowed up in the system” and not receive the level of support they need. A disability employment consultant commented: “I would be scared to take that wall away in the middle [specialisation] because I think this side of the fence where we work would just slip away into nothing and that assistance would disappear.” A summary of participant views on the advantages and disadvantages of specialist versus mainstream employment services is presented in Appendix M.

There was widespread acceptance of the value of employment services employing people with a lived experience of a mental health condition, who were perceived to be better able to empathise with jobseekers with a mental health condition. Some respondents were in favour of employment services engaging peer support workers. One employment service provider suggested that peer support roles could be adapted to best utilise their experience to provide on-site support for people working with mental health conditions. One former peer support worker, however, recommended that more people



with lived experience be employed in employment services as “normal” workers. A peer support worker, in describing the drawbacks of the role, explained: “Sometimes...I just want to be a worker, not a.... I don’t know what you’d call it ...it’s like you’re an item for display. ‘Here’s the consumers [patients]’...” Some health professionals, however, expressed concerns about peer support workers in relation to their awareness of personal boundaries and level of knowledge and understanding of mental health conditions. Employment consultants felt that improving pay rates of employment consultants might assist to attract quality staff, retain skilled and experienced staff and reduce recruitment costs in an industry where there reportedly is high stress, burn-out and staff-turnover rates.

Funding issues in relation to employment services focussed mainly on recognition of the additional work involved in assisting someone with a mental health condition into employment and the need for more resources to be directed into the training of employment support personnel:

I think the government needs to educate the employment agencies in the fact that ....it’s not a numbers game. Some [jobseekers] do need that extra care and if you give them that extra care they could stay in that job longer because it’s something they do want to do. (Ex-employment service provider)

A need was also expressed for funding levels to recognise the level of support required for people recovering from chronic and/or severe mental health conditions to transition back into the workforce. Employment consultants expressed the need for funding to enable more individualised attention and care for jobseekers with mental

health conditions. Extra time and care may be needed to create individualised resumés, provide encouragement to build confidence and find a good job fit to ensure sustainable employment. This involves consideration of activities that the jobseeker needs to build into their routine to maintain their health, and then arranging the job around this. An ex-employment consultant suggested that government needs to educate employment service providers that “it’s not a numbers game” and that more heart is needed. A carer talked about the need for job agencies to show more understanding and compassion. It was suggested that some employment services may need to be more responsive to jobseekers who approach their services, and provide timely outcomes while jobseekers are still keen, otherwise they may give up. DES consultants said they would like to have access to funding along similar lines to mainstream employment services to provide jobseekers with the basic necessities for job-seeking, rather than this expenditure having to come out of the company funds.

There was a call for more government responsibility to ensure consistent standards of employment service provision to clients with mental health conditions. Representatives of various stakeholder groups recommended more funding to provide training for employment consultants in mental health. Employment consultants were seen as playing a role in educating employers but as also having a need themselves for more education and awareness. Employment service consultants expressed a need for more training in mental health including better understanding of the subjective experience of mental illness:

I think we need some good in-depth training programs on mental health. We put everybody [employment consultants] through mental health in the workplace [training] when they come in and give them as much ongoing training as we possibly can but we also tend to refer clients with significant mental health issues to...our psych trained and our AOD [alcohol and other drugs] counselling trained employment consultants. But anything we can get our hands on for everybody else that doesn't have that tertiary level we just grab.” (Employment consultant)

Another employment consultant expressed a need for deeper understanding of the subjective experience of psychosis:

...if I had a magic wand I would actually give myself that mental health illness [sic] so I really knew and understood what they were living with...but then I'd have to change it back again (laughter) because I wouldn't want to live with it, but I know I don't understand the depths of it, how could I possibly?...I think I'd want to experience it so I'd really know. 'Cause I think that would make me a better worker to help them.

Some respondents felt that there is lack of adequate understanding of the post-placement support needs of employees living with psychosis.

**Training policy.** New initiatives in training policy were suggested including identification of individual jobseeker skills and abilities with provision of subsidised education and training opportunities in targeted areas of skills shortages, as well as training subsidies to enhance the skills of people already in employment.

...let the government fund them in getting a skill that is needed...that might even give them more of a sense of being, because not only do they have a job, but they've got a skill that other people don't have. (Community member)

Education of all managers and HR personnel in mental health awareness was suggested, including how to promote positive mental health in the workplace. A community participant suggested the need for another branch of workplace health and safety called Workplace *Mental* Health and Safety. It was suggested that mandatory mental health awareness training should be part of government occupational health and safety criteria in all workplaces

I think that every employer should have a module understanding mental health and the workplace...It's like a government criteria [sic]. You need to know this and you need to understand it and you need to take people into the work, you know, offer people the same opportunities. (Employment consultant)

It was also suggested that the costs associated with this training should be borne by the government. Training of peer support workers for work in the employment service industry was also proposed.

**Social security changes.** There was a call for the government to recognise the long-term benefits of employment for people living with these conditions and to provide more incentives, rather than penalties, for people on a disability pension who return to work. It was suggested more people with these conditions would work if working had less immediate and significant impact on their rate of social security payment. Several respondents suggested the government should invest money in allowing people to keep

their disability support pension for a longer period after commencing work, to enable them to become conditioned to working and experience the benefits of work before their payments are reduced or cancelled:

They need to let them keep that [disability pension]. Let them get used to a pattern of working longer hours so they get used to and it's part of their lifestyle but also that they get used to... "Ah it's good to have this money" and let them get a chance to support them, to be able to get promotion too, get more educated so they can actually apply for higher paying jobs and then it would be worth it...

(Peer support worker)

Some participants even felt people on DSP who return to work should retain all of their entitlement. A client with schizophrenia suggested, "...if you could have a system where you could have employment and just keep that money and not lose any of your pension because of it, that would be much better, more incentive to work." An occupational therapist recommended financial incentives and concessions to encourage disability support pensioners to return to study. A client participant suggested that disability support pension recipients should be provided with computers.

A former employment provider felt that people with these disorders need more encouragement to work and understand the benefits of work from their treating health professionals as well as government agencies concerned with employment: "I do think they do need more encouragement [to work] rather than just being one of a number." A DES manager commented:

...these people have sometimes been on the DSP for three or four years and they haven't had any interaction or connection or anything to say that you could be a valuable employee to somebody... somebody needs to wave a magic wand over the DSP department and say, "Let's look after these people and bring them back into society as well".

A customer service advisor agreed on the need for "... motivating the person...to be able to see, yes, there is going to be something out there for them [and] being able to follow through with that".

Participants in this study acknowledged the importance of social security payments for vulnerable individuals and expressed concern about the negative impacts of any form of coercion or compulsory job-seeking for people with severe mental health conditions. It was pointed out that there is an important difference between "having all the doors open" and being "forced through the door".

**Education policy.** Education policy changes proposed by respondents included introduction of education around mental health from an early age with the goal of reducing the stigma. A school principal remarked, "I think that's the *only* way, in a way, formal education. Historically...it takes time [but] that's where most change occurs." A number of community participants, including school teachers, suggested innovative ideas regarding how education on mental health conditions could be integrated into the regular school curriculum.

Participants also identified a need for early intervention to address the disengagement from education, training and employment that can occur among young

people with these conditions. Employees with qualifications and skills were seen to enjoy better working conditions, with more scope to tailor the work role around their mental health needs. The advent of flexible schooling options and disability support services at tertiary educational institutions were endorsed. One participant suggested a need at tertiary level for more individualised mentoring support, tailored to individual academic needs.

Participants identified a need for change in the tertiary education of health professionals, specifically for health professionals to develop greater awareness of the health benefits of work and to adopt a more positive, optimistic and recovery-orientated approach. It was suggested that education of psychologists should equip them not only with the skills needed to manage symptoms but also an understanding of the importance to psychological wellbeing of functional outcomes such as employment.

#### **More integrated support.**

Participants expressed a need for more integrated service delivery, described as a more co-ordinated, multi-disciplinary, multi-service approach. This would involve closer working together, partnerships and integration of services involved in providing care and prevocational services. In particular, the need was expressed to strengthen ties between mental health and employment services. A psychiatrist suggested that the employment agency or a worker should be “embedded” with the mental health service and integrated with prevocational services. It was suggested that achieving better integration would cost money, time and resources. Participants felt the government should fund the various sectors appropriately and *expect* them to work collaboratively towards achieving common

goals. This would include exchange of relevant information about the nature of services provided, efforts to make services more user-friendly and provision of feedback on outcomes. This would require careful selection of clients who would and would not benefit from this approach, and simplifying bureaucratic processes around client consent to share information. More cross-communication between federal, state and community organisations would better inform assessments and recommendations and meet holistic support needs. Centralised case management forums for selected clients were also suggested.

The need was identified for more proactive efforts to link clients with employment services prior to discharge from hospital, particularly in those instances where the person is not case managed. A patient advocate felt that a key need is for support to make a graduated transition back into to the community following hospitalisation. A need was expressed for a transitional program, where clients who have been discharged from hospital can receive support to effectively address pre-vocational needs and build work skills that would prepare them for the challenges of job-seeking and the demands of a work situation. The potential role of carers in case discussions about employment was recognised. More holistic care by general practitioners, linking people with psychotic conditions into a range of social support services from an early stage, was recommended. It was suggested that psychologists in private practice in the community could work in a more integrated way with disability employment services.

Health professionals, both in the public and private sector, acknowledged that improved communication among relevant agencies involved in employment would be



beneficial. Employment consultants indicated that access to relevant background information would help inform employment-related assessments. Health professionals in the public sector indicated that they would value more regular communication and feedback from employment service providers. They felt that there were several benefits to be derived from improved communication: clinicians could learn much from knowing how their patients present in public whilst seeking employment or working; it would be rewarding for health professionals to obtain feedback on positive employment outcomes; it would help to ensure that support needs are effectively met; and avoid duplication of services. Some suggested that in true integration, DES and job network services should become one integrated service with capacity to assist all types of clients.

### **Role of Non-Government Organisations**

A client participant proposed more government funding for non-government agencies in capital and regional cities to provide prevocational support and employment-related programs. There was a call for expansion of the Clubhouse service model, which was seen to play a valuable role in the provision of social and prevocational support (life skills, budgeting, social skills, computer skills), providing work experiences and building work stamina. It was suggested that non-government community organisations promoting mental health should provide access to computer facilities to support computer literacy among people with long term mental health conditions. It became apparent that some people living with psychosis may be mistrustful of organisations delivering government services and programs and would prefer to engage with a non-government or community organisation. For these people non-government

organisations (NGOs) were seen as a more acceptable option for work re-engagement services. There was a suggestion that due to trust issues NGOs that provide counselling services would be better placed than government organisations to initiate discussions around career planning and facilitate engagement or re-engagement with work or study. It was felt that people with lived experience working for a not-for-profit community organisation would be well accepted as facilitators in this process. A politician considered that NGOs could be better funded to facilitate employment outcomes. There was also a suggestion that NGOs could be better funded to find work opportunities and financial backers to create competitive employment opportunities for people with mental health conditions, where employees can work in a supported environment and get paid at award wages. It was also felt that employment in NGO roles would provide a career pathway for some people with lived experience of psychosis. Non-government organisations were also seen to potentially have a role in assessment for purposes of employer subsidy schemes and in raising awareness in the business sector. NGOs such as Lifeline were seen as a possible source of emergency support for employees. Two participants suggested retirees and local community support groups could play a role in providing workplace supervision as well as skills training, mentoring and pastoral care.

### **Positive Media Messages**

The media was recognised as an important vehicle for change in public perceptions and attitudes. Participants felt the government could use the media to educate

the general community on how to identify early signs of not coping and where people can access treatment services:

...you can't really walk into the hospital and say "Look I've got a mental problem". Who ya going to talk to? The secretary? What do I do with ya? You know, it's not her....she [has] got no idea what's going on. And no one knows where to go, you know. You pay all this money for advertisements give up cigarettes, give up this, give up that, costs money for this but, as I said, *no one knows where to go if you need help if you're cracking up.* (Community member)

Participants perceived a need for more positive media coverage. Most participants were supportive of TV ads and use of the radio to normalise and de-stigmatise the more severe of forms of mental illness. It was felt that education through the media would be a powerful and effective means to improve understanding and challenge popular stereotypes around psychotic conditions. One participant questioned the cost-effectiveness of this approach given the magnitude of stigma, and suggested there may be a need to consider other strategies:

Stigma is a big, big thing and having just some ads that run for a limited time is not going to change the overall...it might trigger a few people to say something or have a few conversations about it but I don't think that it will change the big thing. (Peer support worker)

Participants felt there was a need for more positive stories on television about healthy, happy people who are coping with their condition, particularly successful people such as prominent public figures and sports stars. There was also a call for TV shows to

incorporate positive role models of people living with psychosis and effectively managing their conditions:

I know this might sound controversial but have like TV shows and things like that, or like have them integrated into your media...and not kind of portray them as sick people. Portray them as capable individuals that can do work and who can have a normal life, because I think TV affects a lot of kids as well...and it's like the quickest and easiest way...to people. (University student)

There was a need expressed for greater public awareness of restoration provisions for DSP recipients who voluntarily return to work, and wider publicity of programs to support people whose job is in jeopardy.

Employment service providers talked about the need for more publicity in newspapers and radio stations of “good news stories” to increase employer awareness of successful employment placements:

...there's the odd employer that is starting to say, “Well I really want to help somebody with disability.” So we're hoping to be able to build on that... get that good news story out there and get some more media of some kind on it. Really, you know, get it in the newspapers or on the radio station. (Employment service manager)

Some participants referred to movies which elicited empathy and hope in contrast to the majority of movies which appear to reinforce existing stereotypes. There were also signs of change:

Every time the government runs a television or a media blitz on employing people with blah, blah, blah conditions, things improve. There's also more of an awareness of how wide-spread these issues are in the community. It's not hidden anymore so employers are receptive to employing a person with a mental health condition. I really believe they are. (Rehabilitation consultant)

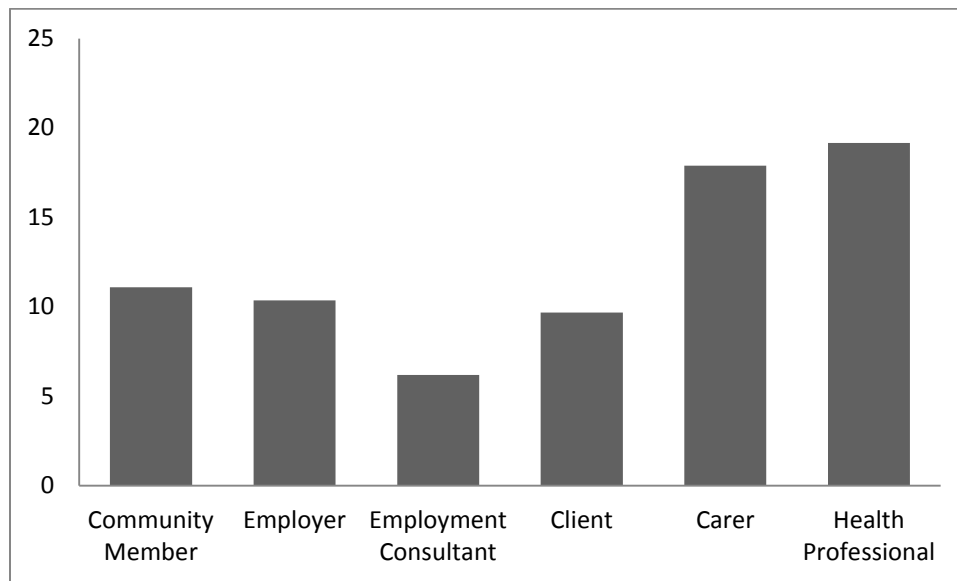
A politician commented on the need for more recognition of journalist and media people who show leadership in responsible reporting: "We need to encourage our reporters, our journalists, our media people to look more positively and see how they can promote good mental health."

### **Research**

Research was mentioned as another area of need with focus on tertiary research projects and improvements in medication. The importance and value of the current research project was endorsed by many participants.

### **Summary of Systemic Change Needs**

The main systemic change needs were in the area of government policy (423 references). The most frequently referenced government policy changes were in the areas of mental health policy (145 references) and employment policy (120 references). The total number of coding references to systemic changes according to stakeholder group is shown in Figure 53.



*Figure 53.* Average number of references to systemic changes according to stakeholder group.

### **Summary of Overall Employment Support Needs**

Employment support needs could be broadly categorised as, culture change, employment assistance needs and systemic change. The most frequently referenced employment support need overall was for more effective employment assistance. A comprehensive summary of employment support needs is presented in Figure 54. A schematic diagram of employment support needs is provided in Figure 55.

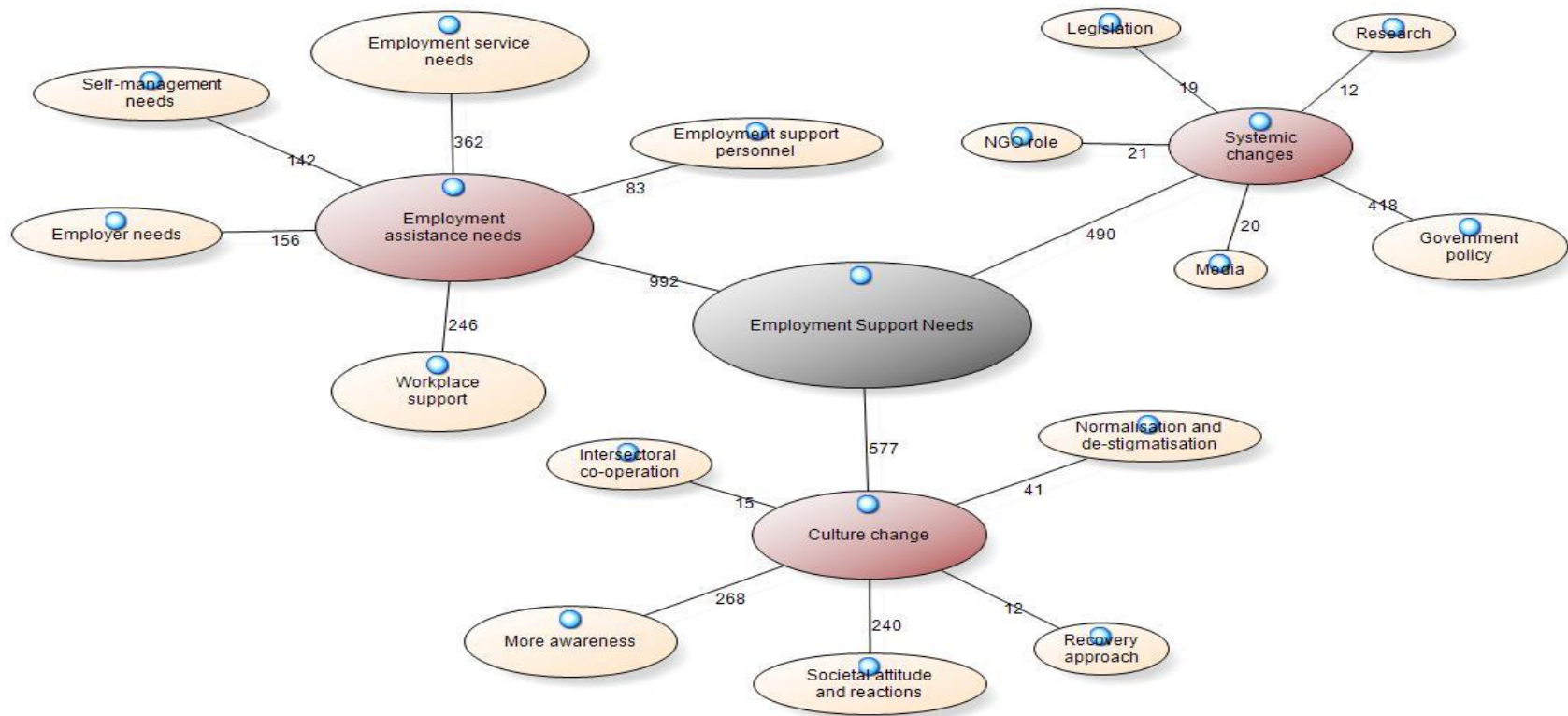


Figure 54. Comprehensive model of overall employment support needs. The numbers entered adjacent to connector lines represent the coding density (number of references) by all participants, to each of the main support nodes.

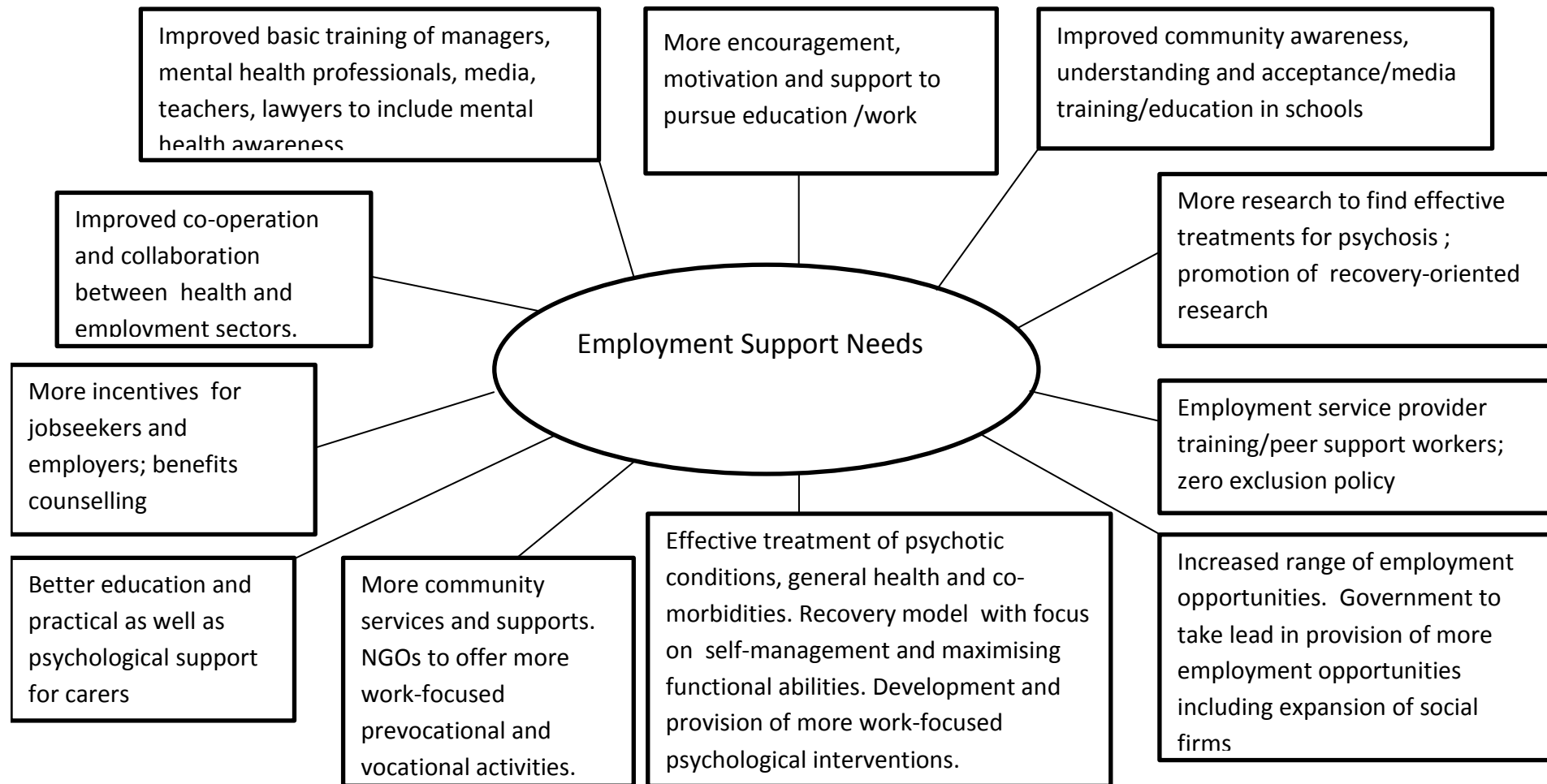


Figure 55. Schematic Diagram Showing Employment Support Needs in Psychosis.



### Comparison of perspectives of six stakeholder groups

Figures 56-61 show the coding density (number of references) to the main employment barriers and support needs within each of the six main stakeholder groups.

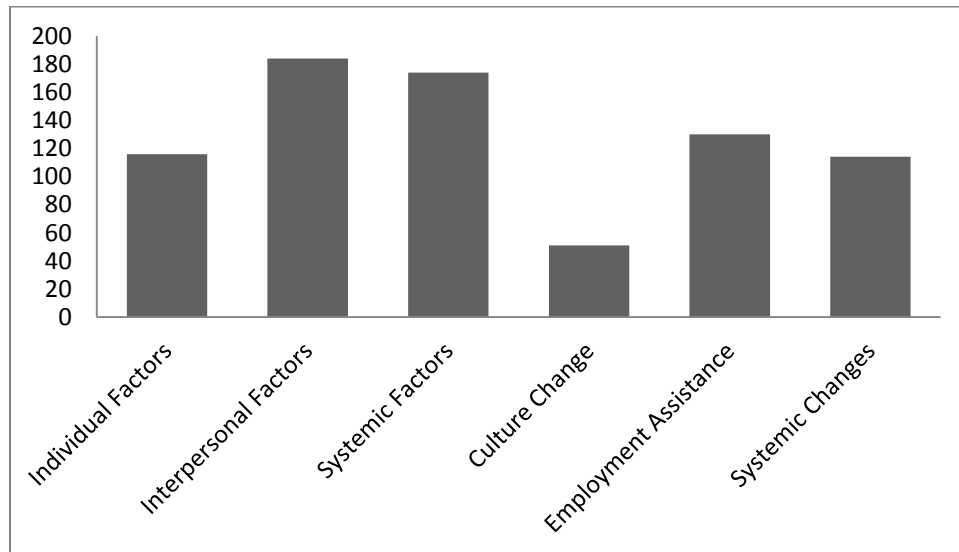


Figure 56. Employer coding density chart for main barriers and support needs.

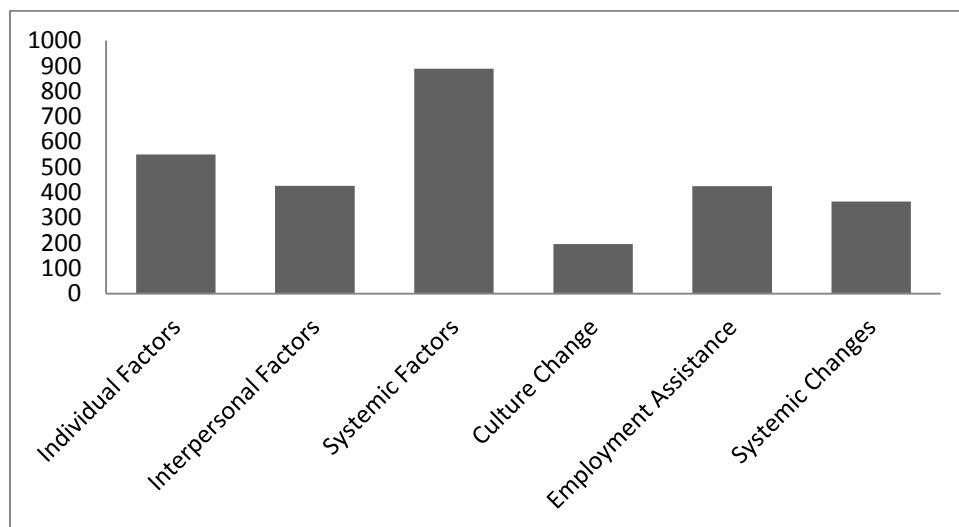


Figure 57. Health professional coding density chart for main barriers and support needs.

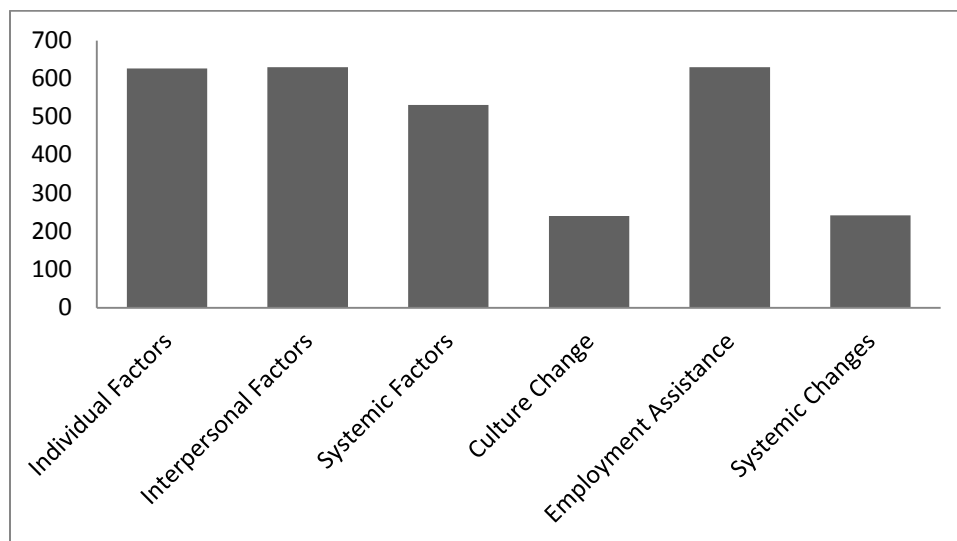


Figure 58. Client coding density chart for main barriers and support needs.

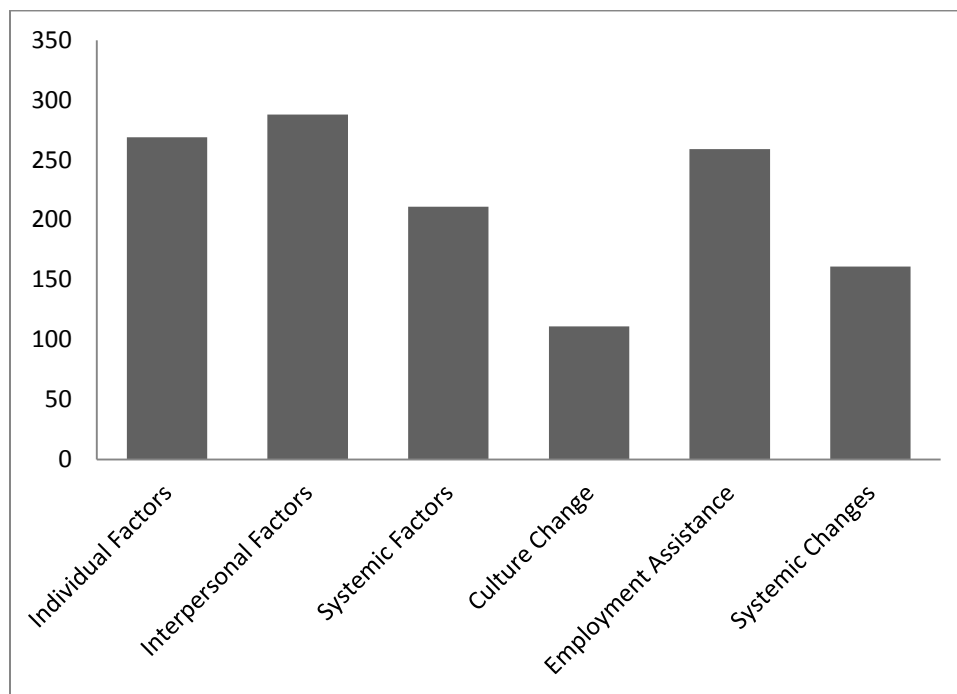


Figure 59. Carer coding density chart for main barriers and support needs.

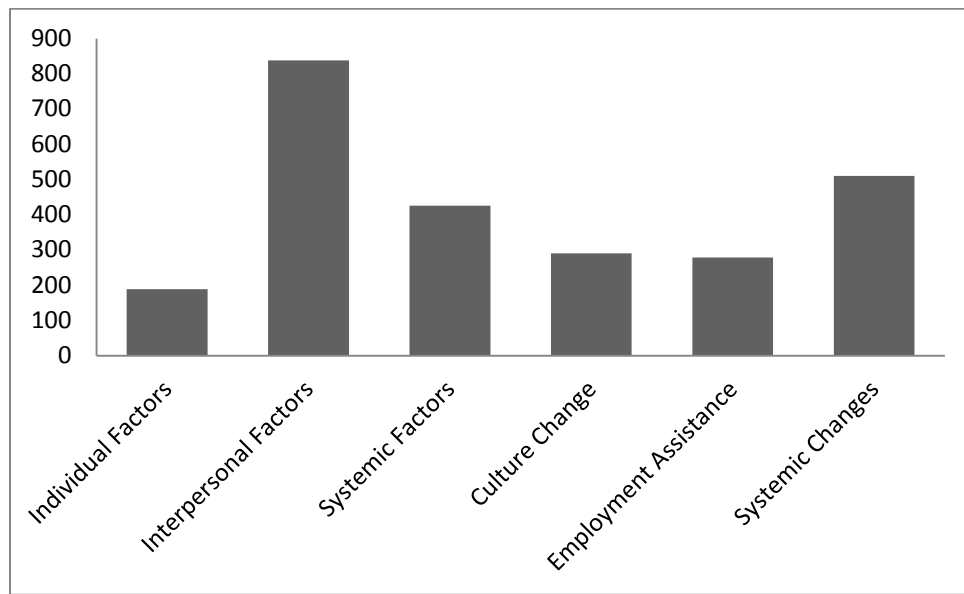


Figure 60. Community member coding density chart for main barriers and support needs.

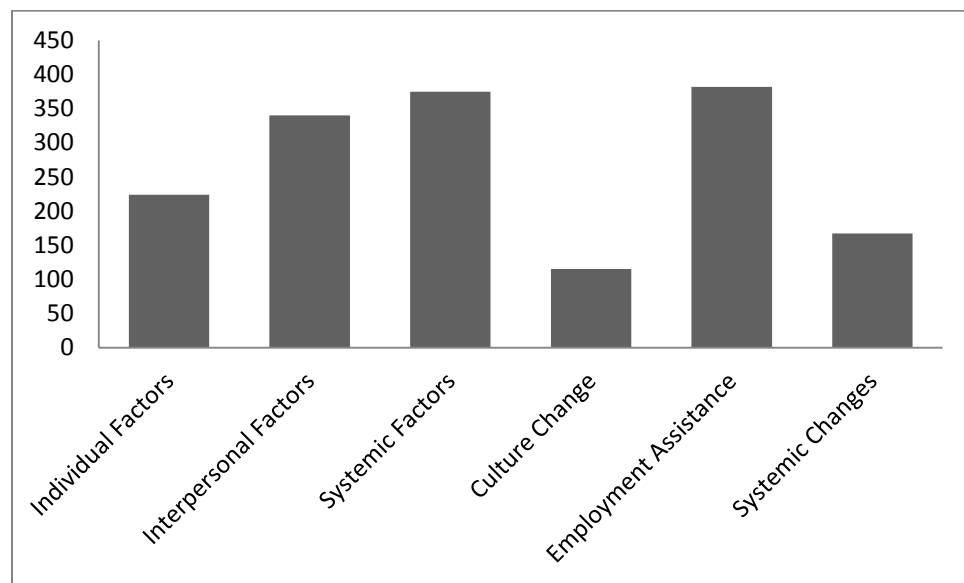


Figure 61. Employment consultant coding density chart for main barriers and support needs.

## **PART C**

### **Discussion and Conclusions**

## **Chapter 14: Discussion and Conclusions**

It seems paradoxical that a cohort of people who centuries ago were excluded from society and placed in workhouses on moral grounds due to perceived indigence, and later transferred to mental asylums (where work was deemed important), are now often excluded from working, even if they so wish. The following discussion represents a synthesis of the literature on employment barriers and support needs of people living with psychosis, insights shared by participants and the researcher's own attempts through this study to understand the status quo. Although the major aim in this study was to identify perceptions by the relevant stakeholders of the barriers and support needs of people living with psychosis, this chapter strives to focus on some of the major threads of relevance to this work and identify possible future directions to improve working rights for people living with the experience of psychosis.

### **Public Ignorance and Opportunities to Learn**

In industrialised societies, institutionalisation resulted in many years of separation of the so-called insane from mainstream society. This long history of segregation from mainstream society may account for the current state of ignorance and intolerance that prevails towards the mentally unwell in contemporary society. One research participant recalled the high walls that surrounded the mental asylums of the past and how “no-one knew what went on in there.” Although the de-institutionalisation movement returned the so-called insane to the community, people living with psychosis remain a socially isolated group, marginalised from mainstream society and largely invisible, and the average person still knows little about the experience of psychosis. The exclusion of

people living with psychotic conditions from mainstream society during the asylum era may have contributed in part to the current lack of community knowledge and ability to respond appropriately to people whose lives are affected by these conditions. A significant consequence of this prolonged segregation from mainstream society is that for many years the average citizen has been deprived of contact with and the opportunity to learn about and understand the world of those experiencing unusual mental states. The *medicalization* of madness during the asylum era served to further alienate the average citizen from the experience of madness, by vesting knowledge and responsibility for psychotic conditions in the hands of an elite few in the medical profession. During the asylum era, madness became the object of scientific study, and *knowledge* concerning *mental illness* was claimed as the domain of medical science. The ever-changing nosology of psychiatry perpetuates the mysteries of *mental illness* and renders it an elitist area, inaccessible to the general public. It is not surprising therefore that a participant in this study described how the general community felt unprepared for the de-institutionalisation movement when it occurred during the nineteen seventies.

Participants in this study identified significant gaps in knowledge and understanding, as well as myths and prejudices that still exist in society in relation to people who have been diagnosed with psychotic conditions. Knowledge of these conditions is still seen to rest primarily in the hands of *experts* in the medical profession. There was recognition by participants of significant gaps in knowledge, awareness and understanding of psychotic conditions across most sectors of the community. Many lack the education, understanding and skills to interact confidently with people diagnosed with

such conditions. Participants suggested that lack of understanding of peoples' abilities and limitations can lead to blurring of role boundaries, overprotection and result in learned helplessness which can severely limit a person's recovery.

Responses referred to ongoing social taboos which restrict public discussion around mental health topics. The taboo nature of the subject in common conversation and its exclusion from the domain of formal education reduces opportunities for exposure to and acquisition of new knowledge and awareness regarding mental health conditions.

Although a number of participants in this study disclosed having a family member, friend or acquaintance diagnosed with a psychotic condition, the low incidence of psychotic conditions combined with the prevalence of non-disclosure and tendency to self-isolation leaves the general public with limited opportunity to learn. The under-representation of people with psychotic conditions in the workforce further reduces the visibility of these conditions and limits opportunities for social learning, to improve public knowledge and awareness, and to challenge negative stereotypes. Unless an immediate family member is affected, exposure and learning usually only occurs later in life. Bipolar disorder and schizophrenia are rarely diagnosed during childhood therefore children have little exposure during their school years to peers exhibiting these conditions.

Mental disorders tend to be less visible than physical deficits, further reducing exposure and opportunities for social learning experiences. Unlike employment of people with physical disabilities, where employment is synonymous with exposure, in mental health conditions employment may involve exposure without public awareness and

therefore the desensitisation process that occurs with physical abnormalities cannot be assumed.

The decision to release this cohort of people into the community some thirty years ago was reportedly made without community consensus or preparation for what essentially was a momentous change (Talbot, 2004). Indeed, large scale formal and informal public education is yet to occur and most people still rely heavily on information provided by the media. In the absence of formal education, the media is seen to play a powerful role in shaping public knowledge and perceptions. This may explain why the media currently exercises such a powerful influence over people's perceptions regarding psychotic disorders. Currently, public perceptions appear to be shaped predominantly by the media particularly movies. In the absence of knowledge and personal experience of people with psychotic conditions, public attitudes and decision-making (including those of employers) are influenced by reified images which are inaccurate and derived largely from media images.

In summary, the following factors were identified that perpetuate public ignorance: 1) low incidence of psychotic conditions 2) invisible nature of these conditions 3) low employment rate 4) non-disclosure 5) taboo nature of the subject 6) lack of formal education 7) social isolation and 8) social exclusion.

### **Stigma and Discrimination**

Contempt for the mentally ill is an historical phenomenon that is deeply ingrained in what Durkheim terms the collective consciousness of society (Durkheim, 1897/1997). Doubtless remnants of the humiliation and inhumane treatment of this historical period



still loom large in the common consciousness of modern society, finding expression in common preconceptions, misconceptions and linguistic phenomena. In this study, contemptuous expressions such as “mad as a hatter”, “mad as a cut snake”, “completely barmy” were used by participants with impunity and considered humorous. Many years of ridicule and exclusion from society have resulted in the public being alienated from the experience of everyday interaction with people with these conditions. Although people with psychotic conditions are no longer publically ridiculed as in previous times there still remain remnants of the stigma and ridicule meted out in previous eras.

The most frequently referenced barriers to employment in this study were interpersonal factors, notably stigma. Fifty years after Goffman’s classic work on stigma and mental illness, it is apparent that stigma still has a powerful impact in the area of employment of people living with psychosis (Goffman, 1963). This study confirmed that people diagnosed with psychotic disorders tend to be viewed as an homogenous group and are subject to social stereotypes in which salience is given to diagnosis over all other personal qualities and characteristics. The result is a tendency to attribute personal characteristics based on diagnosis and overlook important and unique individual differences in personality, values, strengths and abilities.

A number of factors interact to perpetuate stigma associated with psychotic disorders. Stigma is perpetuated by lack of knowledge and understanding among ordinary members of the community. The low incidence and visibility of people living with these conditions and their relative social exclusion from mainstream society allows the general public few opportunities to challenge stereotypical notions. The ongoing exclusion of

people living with psychosis from the workforce prevents community members obtaining first-hand experience of people living with these condition which serves to perpetuate anxieties and prejudice.

Participants in this study reported that community ignorance regarding psychosis induces fear and discrimination. Due to lack of knowledge and understanding of mental illness, community members including employers perceive people living with psychosis to be an unknown risk and respond with fear and suspicion. The vacuum in public knowledge, fear of the unknown, uncertain risks as well as a perceived lack of competence interacting socially with people with these conditions serves to increase social distance, reinforce negative stereotypes, and perpetuate social exclusion and social isolation. Fear of the unknown and lack of skills to deal with these conditions may also result in avoidance of interaction and poor service standards. All the above prevent society from developing a more comfortable and constructive relationship with people living with psychosis. Social distance, due to exclusion from the economic life of the community, in turn serves to further entrench suspicion, negative stereotypes and discrimination. This creates a vicious cycle, which perpetuates ignorance, fear, suspicion, avoidance and social exclusion. Episodic public acts of violence and negative stereotypes portrayed in the media reinforce fear, suspicion and the exclusion of the mentally ill from social and economic participation.

Participants in this study suggested the expectation of and fear of violence is an important source of stigma and unwillingness to employ people with psychosis. The results of this study showed misunderstanding of risks associated with psychosis as

exemplified by the frequently referenced stereotype of violence. Concerns expressed by participants about risks of violence associated with employing people with psychosis highlight a need for better understanding of the risk factors associated with violent behaviour in psychosis. There remains considerable ambiguity, even in the professional literature, about the link between psychosis and violence, Elbogen & Johnson (2009) suggest that co-morbid substance misuse, post-traumatic stress disorder, personality disorders as well as environmental stressors (including unemployment and victimisation) may account for most of the violence associated with psychosis. Indeed, research indicates that people living with mental disorders are more likely than the general population to be victims of violence (Crump, Sundquist, Winkleby, & Sundquist, 2013; Hiroeh, Appleby, Mortensen, & Dunn, 2001). Torrey (2011) maintains that most episodes of violence committed by people with serious mental health conditions are due to lack of effective treatment, which he therefore considers an important factor perpetuating stigma.

A paucity of positive media messages and a focus on danger, violence and unpredictability serve to reinforce and perpetuate negative stereotypes and stigma. In addition, ignorance and negative media messages generate fear in the public consciousness. Although there are many notable high-functioning people in society who have been diagnosed with psychotic conditions and successfully manage their conditions and careers, strong social taboos still exist which prevent disclosure and sharing of positive stories of people leading meaningful and contributing lives in spite of symptoms.

In summary, fear of the unknown, negative media images and episodic acts of violence that are poorly understood contribute to perpetuating stigma and economic

exclusion. Lack of understanding may lead to faulty assumptions and expectations, which can negatively impact the quality for life of people living with these disorders. Indeed, the research findings of this thesis suggest that the high walls of those asylums still exist today in a metaphorical sense by way of ignorance, segregation and discrimination.

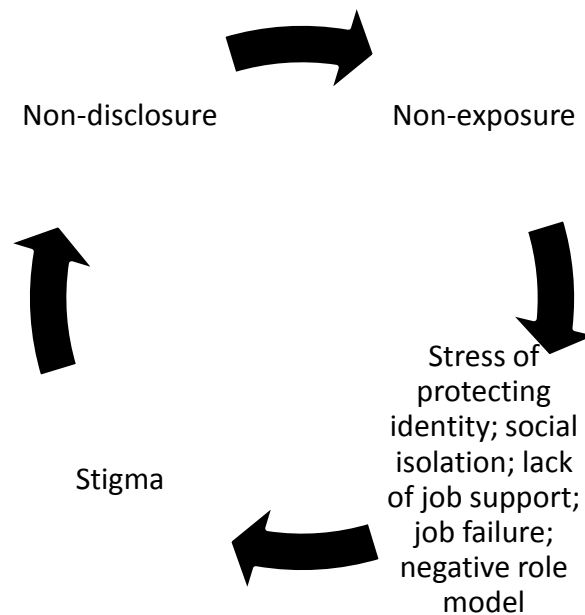
While the expansion of easily accessible and user-friendly services for young people diagnosed with a psychotic condition is an important measure, social stigma and negative stereotypes towards mental health impact on help-seeking behaviour.

Adolescents in particular are sensitive to prevailing social attitudes held by family, friends and peers and portrayed in the media. Overcoming the social stigma associated with mental illness is essential to promoting help-seeking behaviour and is an important goal which must be addressed if young people are to avail themselves of treatment and employment services provided.

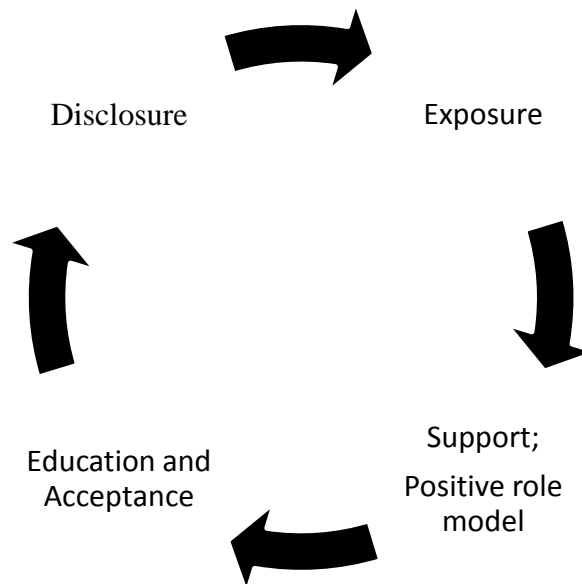
Stigma results in a tendency to react differently to people whose physical and behavioural differences are poorly understood by others. Many people themselves do not enter employment or access disability employment services due to fear of stigma and discrimination. Stigma in the workplace perpetuates the social isolation experienced by people with serious mental illnesses in the community as it affects the quality of social relationships that are possible in the workplace. In addition, stigma seriously restricts the capacity to form and sustain mutually satisfying and meaningful relationships with co-workers, which generates its own stress for the stigmatised.

This fear of stigma and discrimination may lead to non-disclosure to an employer, with consequent lack of employment support in the event of a relapse. Some workers tend

to be secretive about the condition and either not disclose or partially disclose a condition in the workplace, thus limiting the opportunity for co-workers to be consciously exposed to these conditions. The need to conceal the condition from employers and co-workers can itself generate increased work-related stress with resultant exacerbation of symptoms, decreased ability to cope and reduced capacity to retain employment. These factors interact to create a self-perpetuating cycle in the workplace (See Figure 62).



Conversely:



*Figure 62.* Self-perpetuating cycle of stigma in the workplace.

### **Role of Health Professionals in Perpetuating the Status Quo**

Despite living in the community, some community residents living with psychosis were described as “institutionalised”, and the impacts of psychiatric “care” are still taking their toll long after the asylums have closed. The main focus of medical treatment of psychotic conditions continues to be the management of symptoms through use of psychotropic medication, hospitalisation and case management. One might expect that health practitioners, as custodians of knowledge and understanding about mental illness, would champion the cause of social inclusion, including participation in work, study or community participation. On the contrary, health professional attitudes and behaviour in general, as reflected in the comments obtained in this study, may not be conducive to employment outcomes. Indeed there are a number of factors associated with the medical

model that compromise the employment prospects of people living with psychosis, making it part of the problem rather than part of the solution. These include clinician attitudes, expectations, beliefs, assumptions, and practices; factors intrinsic to the clinician-patient relationship; and factors inherent in the language of the medical model.

One factor that reduces employment prospects is that health professional attitudes may be biased due to the “clinician’s illusion” (Cohen & Cohen, 1984). Health professionals who work in clinical settings are disproportionately exposed to patients who are acutely or chronically unwell, and may not gain the same degree of exposure to people with psychotic conditions who are functioning well and leading normal lives in the community. This selective exposure may influence clinicians’ expectations of recovery. Research confirms that health professionals tend to have low expectations of the capabilities of people living with these conditions (Marwaha, Balachandra & Johnson, 2009). These lowered expectations when communicated directly or indirectly to clients adversely affect hope and motivation. The present study found that health professionals were more concerned than any other stakeholder group about the impacts of the condition itself as a barrier to employment, lending support to the concept of the clinician’s illusion. Clinicians in this study commonly expressed concerns about the risk of relapse due to stress associated with work, which may explain why some participants perceived there was a lack of encouragement to work.

Clinicians also appear to be unwilling to challenge fixed historical beliefs about the poor prognosis for certain conditions such as schizophrenia in spite of research evidence indicating significant recovery rates (Cohen & Cohen, 1984). The Kraepelinian

view on the inevitability of cognitive decline in schizophrenia has remained essentially unquestioned for almost a century and may account for the pessimistic outlook and seemingly low expectations of health professionals in relation to work outcomes (Kraepelin, 1971/1919). Clinician beliefs about cognitive decline in psychosis are often based on observations of the most severely affected patients in the public mental health system and may be another example of the clinician's illusion (Cohen & Cohen, 1984). Participants identified a danger of stereotyping people with schizophrenia as there is variability in levels of cognitive functioning among clients, some of whom may operate at a high level intellectually. Although the value of medication in controlling positive symptoms is well recognised, the negative impacts of anti-psychotic medication on cognitive functioning reported by participants in this study do not appear to have received sufficient attention in the research literature. There also appears to be insufficient research on the role of social isolation and under-stimulation in cognitive decline in psychosis. Similarly, the negative impacts on cognition of deprivation of intellectual stimulation due to long term unemployment may deserve further attention. Furthermore, the current body of research evidence on the nature and direction of any relationship between measures of cognitive functioning in psychosis and work performance remains equivocal.

Another limitation of the medical model is that the focus of attention tends to be on deficits and disability rather than ability, strengths, competencies and potential of the person. Clinicians are trained and adept at identifying deficits and factors that would interfere with working. Preoccupation with symptoms may result in a tendency to overlook or minimise the importance of, or the desire to work. Findings of this study



suggest some health professionals still do not really believe that people living with psychotic disorders can work. Clients who have personal strengths and abilities as well as a desire and ambition to work are sometimes regarded as having “unrealistic expectations” or “lack of insight” and clinicians may also feel a need to protect patients from failure which tends to immobilise action in pursuit of work goals.

In the medical model, there is also a tendency to assume patients are incapable of working until or unless they are symptom-free. This may be appropriate in the case of some, though not all, physical conditions. However, many clients with severe and persisting mental health conditions, despite optimal treatment, may continue to experience residual clinical symptoms as well as side-effects of medication throughout their lives and may never be symptom-free. Due to the presence of ongoing symptoms such people may be deemed “not work ready” and are therefore at risk of prolonged unemployment.

Health professionals seeking to treat psychosis tend to focus primarily on achieving symptom remission rather than functional recovery and often quite erroneously assume that the former will necessarily lead to the latter (Waghorn, 2011). Negative symptoms of psychosis such as amotivation tend to be less responsive to antipsychotic medication and may constitute major impediments to functional recovery, yet to date there has been no indication that any form of intervention could or should be attempted to improve the motivational status of people living with psychosis.

Research reports suggest that health professionals may not be fully aware of the significance of employment as a major determinant of health outcomes or their

responsibility for managing long-term work absence or unemployment (The Royal Australasian College of Physicians, 2010). Responses of participants support the view that some health practitioners do not appreciate the importance of employment in improving mental health status in serious mental health conditions. Despite the value of employment as a form of behavioural activation and the known ill effects of ongoing social isolation and unemployment, the medical profession tends to confine their role to medication and generally tend to feel less responsible for integrating or re-integrating their patients into employment. This raises the question of whether lack of specific funding for supporting employment outcomes plays a role in the prioritisation and seemingly laissez-faire approach to employment observed among mental health professionals.

Current medical practices in relation to people with severe and persisting mental health conditions tend to reinforce a system geared to exclusion. Health practitioners often enable long-term absences from the workforce and may perpetuate unhelpful beliefs about the potentially adverse impacts of work on medical conditions. These beliefs and opinions, when communicated to clients and significant others, powerfully shape and influence decisions about engaging in work-related behaviours. However, protecting a person from all sources of stress is unlikely to help people to build resilience or skills they need to cope with the demands of everyday life and is likely to reinforce the avoidance that is characteristic of many mental disorders. Avoidance is a characteristic of many psychiatric conditions, and enabling non-participation through unnecessary sick certificates and exemptions tends to entrench the tendency to avoidance, resulting in loss

of confidence, long-term unemployment and its concomitant de-skilling, de-conditioning, and increased anxiety and depression.

Liberalistic and laissez faire views on the part of health professionals concerning client decisions around work, while ostensibly benevolent, may simultaneously provide justification for a lack of attention to the need for active efforts to ensure their successful accommodation in the workforce. This approach was discrepant with the views of most community members and client participants, who regarded employment in socially valued roles as part of normalcy and essential to enjoying full citizenship. This raises the issue whether some of the ostensibly “ethical” positions adopted by health professionals in relation to work may in some way be supporting the dominant ideological structure. It was noted a seemingly laissez-faire approach to employment, in the style of permissive individualism, was in contrast to the strict compliance approach to medication. There also seems to be a fundamental contradiction between the power to enforce involuntary treatment when people's behaviour violates social norms and hesitancy about "pushing our opinions onto people" about employment. Anxiety about ethical issues may relate in part to lack of confidence on the part of health professionals in their ability to facilitate positive employment outcomes.

There is also an assumption in the medical model that the main barriers to employment are intrinsic to the individual. However, this study found the most significant barriers are external to the individual in the form of societal attitudes, stigma and system restrictions. High turnover of staff in mental health services, neglect of employment matters, and fragmentation of services involved in achieving employment

outcomes were identified by participants as systemic factors perpetuating the status quo. Furthermore, the clinic-based treatment model results in a situation where treating health professionals do not have the opportunity to observe their patients in a work situation and often receive no objective feedback on their work performance.

Another compounding issue in the medical model is the nature of the clinician-patient relationship. The boundaries of the clinician-patient relationship and pressure on consultation time may restrict a holistic understanding of the person as a unique individual with potential strengths and abilities. The boundaries of the therapeutic relationship generally preclude clinicians from sharing their own personal challenges or individual or family vulnerabilities, which mitigates against normalisation and perpetuates the dichotomy of “normal” and “abnormal”, and the illusion of the “normal” treating the “abnormal”.

Health professionals also have professional codes that require them to protect patient confidentiality. Participants in this study noted a seeming reluctance and guardedness about divulging information, which is perceived by other stakeholders as essential to effective employment service delivery and achieving sustainable employment outcomes. Lack of communication and liaison between the various stakeholders involved in employment limits relevant feedback on outcomes and the development of improved practices. Future arrangements need to consider more stream-lined processes for managing privacy and information-sharing in relation to employment matters.

Finally, the language of the medical model is itself intrinsically disabling and limits individual potential. In western society, people who are *sick* are generally not

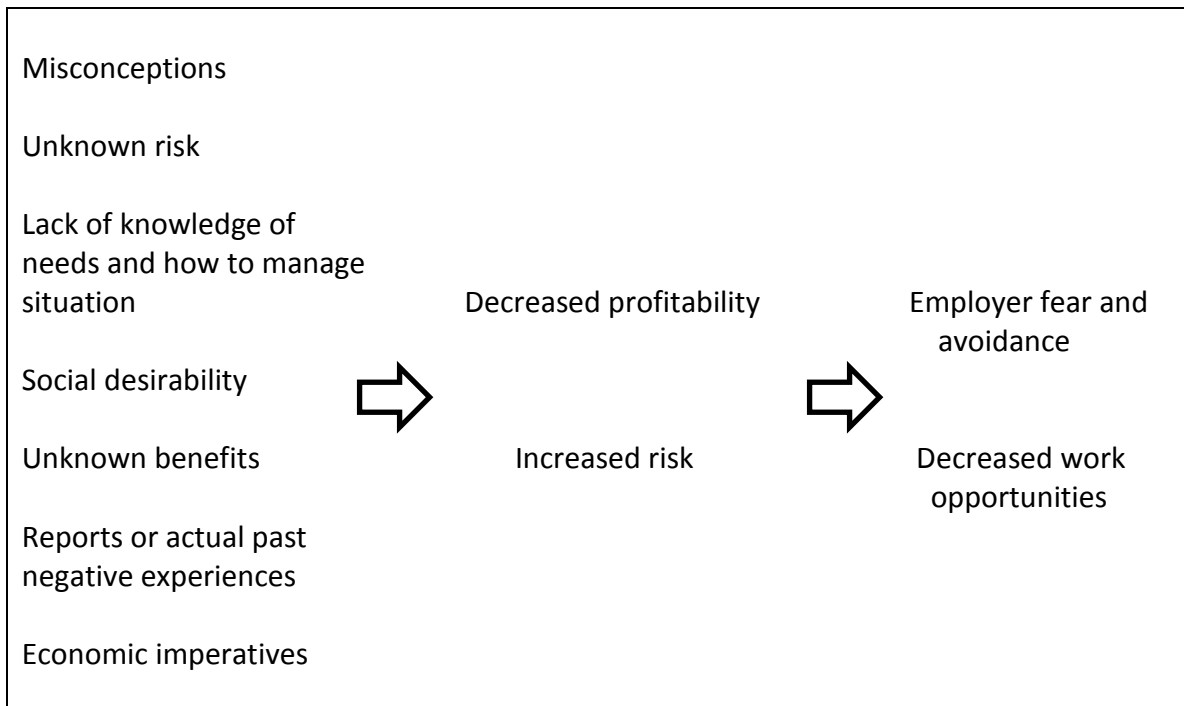
expected to work and it would be considered unreasonable and unkind to expect them to do so. Public and personal expectations associated with the sick role, including lowered demands and protectiveness, are inconsistent with the rigorous demands of job-seeking and work. People who are physically sick usually wait until symptoms of illness have resolved before returning to work. However, in enduring mental health conditions such as schizophrenia or bipolar disorder, symptoms may persist in spite of optimal treatment, and in these circumstances expectations regarding return to work may be unclear. The generally laissez faire approach of health professionals towards job-seeking serves to reinforce expectations which are inconsistent with and do not adequately prepare clients for the realities of job-seeking and work. The contemporary use of the term *consumer*, when referring to mental health service users, ascribes primary significance to being a *user* of services and resources rather than a *contributor* to society. The impacts of diagnostic labelling and in particular the stigmatising effects of diagnostic labels may contribute to loss of self-esteem and secondary depression.

The metaphor of invalidity, commonly applied to people living with persisting mental health problems, influences perceptions of the public and clients themselves concerning their ability to work, with perhaps unintended consequences for their working lives. Participants expressed their views using the language of the medical model, and referred to psychotic conditions using terms such as “malady”, “illness”, “disease”, “sick people” and “disability”, essentially reflecting the disempowering nature of the contemporary social discourse on psychotic experiences. The pre-eminence of the sick role with the tendency to “care for” and “protect” those who are deemed “ill” from

participation in any form of activity until the condition has been cured may work well for some (though not all) physical conditions. However, this is not the case for mental health conditions, where symptoms may be persistent and ongoing. Overprotection can lead to learned helplessness and avoidance of challenge resulting in boredom, social isolation, de-skilling and reinforcement of pathology. Overprotection also tends to reduce opportunity to build resilience and increases stress and anxiety. These are the very conditions that have been found to reinforce rather than alleviate symptoms. Since the medical profession has a powerful position in defining reality, their perceptions are accepted and colour the perceptions and expectations of many carers, patients, employment service providers and other community members. This creates a double-bind situation for clients who are considered to have a persisting 'illness' and yet desire to work.

### **Employers and Co-workers**

This study found that employers tend to prefer to take what they perceive to be the easy option and are influenced by social desirability factors. Participants suggested that there may be a hierarchy of social desirability which influences employer attitudes to employment of people with different types of disabilities. Lack of knowledge about risks, benefits and how to manage a person living with psychosis in the workplace, in the context of drive to maximise profit, creates a dilemma for the modern employer. Factors affecting employer recruitment practices are shown in Figure 63.



*Figure 63.* Employer decision-making process.

There was evidence that co-workers sometimes lacked confidence in interacting with people with these disorders or felt uncertain of the limits of their capabilities. This in turn could lead to development of dysfunctional or disempowering relationships characterised by over-protectiveness and learned helplessness.

### **Employment Services**

Australia has a well-developed and highly funded infrastructure for the delivery of employment support services. Although disability employment services are widely available, they have historically tended to focus on employment service provision for those with physical disabilities and intellectual impairments. It is only during the past decade that there has been an increased focus on the provision of employment services for jobseekers with mental health conditions. The situation in rural and remote areas,

however, still offers little hope for jobseekers living with psychosis due to a lack of available expertise in these areas. The expertise and structure exists in Australia to achieve major social reform in this area.

The results of this study confirm some ongoing difficulties with implementation of the Individual Placement and Support (IPS) model of employment in Australia. Barriers to implementation identified by participants included several barriers to collaboration between disability employment service providers and mental health services. Health professionals perceived a conflict between the IPS principle of rapid job placement and the manner in which clinicians typically prefer to work with their patients. Health professionals in the public mental health sector also felt that while employment services were funded to achieve employment outcomes, there was a lack of recognition that employment is also a health outcome, and health services were not funded to provide employment-related services.

Employment consultants expressed concern that some jobseekers with psychosis referred to their service lacked the requisite understanding of, and preparation for, the demands of work. Inadequate attention to pre-vocational support needs and lack of suitable and supportive employment opportunities may mitigate against successful outcomes. Several respondents argued that rapid placement of people who are not adequately prepared for work into unsuitable jobs with no prospect of career progression is unlikely to achieve sustainable outcomes. Furthermore, rapid job placement into low level jobs where the job conditions may be experienced as more stressful and fail to meet the vocational expectations of participants may not be sustainable. The combination of



clients inadequately prepared for the rigours of work, and pressure to obtain rapid employment outcomes is not productive either for the client's mental health or long-term employment outcomes.

In terms of cost-effectiveness of employment services, studies overseas have found that employment rates of people with psychosis may be higher in some so-called third-world countries than in Australia. A study by Srinivasan and Tirupati (2005) in India found that 67% of their sample of people diagnosed with schizophrenia was employed, most in a mainstream environment. This is a superior outcome to the best IPS outcomes achieved by the highest fidelity evidence-based employment programs in Western countries, and raises the question of whether more attention needs to be given to factors beyond the realm of employment service delivery.

### **Other Systemic Issues**

In some countries, people who hear voices can potentially use this ability in socially valued roles for which they receive remuneration (Jonker, 2006). For example, in South Africa a sangoma is a respected traditional healer. Sangomas are believed to be "called" through an initiation illness, the symptoms of which may include psychosis and somatic symptoms that cannot be cured by conventional methods. After undergoing an initiation process the sangoma assumes an important social role in mediating between the sick or troubled person and the spirit world, and can earn a lucrative living through their gift of divination (Connor, 2008). However, in contemporary Western society there are few remaining social roles in which hearing voices is considered useful, appropriate or a potential source of employment.

Higher than average rates of homelessness and forensic history among people living with psychosis also impact employability. Changes to employment service provision alone will not result in significant change in the employment rate. The process of employment service provision is only one aspect of a much broader picture that needs to be addressed, as many people currently do not use employment services due to low expectations and the stigma associated with disclosure. Wide-ranging systemic changes are required before employment rates are likely to improve among people living with psychotic conditions. While the importance of social security benefits for supporting vulnerable individuals in need was recognised by participants, fear of loss of these payments was also perceived to act as a deterrent for many people to return to work. This has been described in the literature as the “benefits trap” (Olney & Lyle, 2011). The current system of disability support pension payments can become a form of social conditioning in which unemployment, and its accompanying life-style of social isolation and lack of demands, is consistently rewarded. There was a perception among many participants, on the other hand, that the system penalises those who attempt to work in spite of their disabilities. The “reserve” price of work in Australia is very high and the prospect of having social security payments and entitlements reduced or suspended as a result of returning to work appears to be a deterrent for many people. The complexity of calculating financial implications of work and understanding the ever-changing rules around suspension and restoration of such payments are other factors here. There was also a sense that people on DSP may lack confidence in their ability to sustain work and therefore deliberately restrict their working hours/income in order to retain eligibility for

payments. The finding that social security payments pose significant barrier to work lends support for the view of Srinivasan and Tirupati (2005) that welfare benefits may be a major deterrent to work.

Another systemic issue is that an industry is expanding around carer roles. This in itself has potential to create perverse incentives to maintain relationships of dependency that are not conducive to employment. When a carer establishes a working life, carers of people living with psychosis may also need support to adjust, re-shape their identity, and develop and progress their own vocational plans which are usually affected by the caring role (Cohen & Thomas, 1996).

### **Why Work?**

Heuristically, the key to finding the solution for increasing employment in this group may well be to reframe the question. Instead of asking why so few people with psychotic conditions are employed, we should be asking why so many are actually employed, given the extent of the barriers and disincentives. By identifying the factors that influence people with serious mental illnesses to work, despite the challenges they face, it may be possible to obtain valuable information about the latent benefits of work. This information could be used to inform the decisions of others about whether to persist in their efforts to engage in paid employment.

The benefits of work were clearly articulated by participants in this study and are shown in Figure 14. However, in order to realise these benefits certain changes are needed in policies, in public attitudes and workplace practices. Some directions for future research and action are now presented.

**Possible Future Directions****Community education.**

Some thirty years after de-institutionalisation, participants were calling for more public awareness and understanding of psychotic conditions. There is an urgent need to overcome the taboo nature of this subject, de-mystify these conditions and increase awareness among the general public. The formal education system has historically provided an important means to challenge and change social attitudes. This system can play a key role in reducing the social stigma towards mental health conditions. Education was seen as a key to improving attitudes, increasing acceptance and reducing stigma, discrimination and fear. In this age of information technology, disseminating information about mental health conditions can readily be achieved however changing deeply entrenched social attitudes is far more challenging. The issue that remains to be addressed is how attitudes and perceptions can be changed.

Findings from this research suggest that community education may need to commence much earlier, in schools, in order to reduce stigma. An integrated multidisciplinary approach in which the education sector collaborates with the health sector and voluntary organisations to address the problem of social stigma associated with psychotic conditions could help improve education and understanding in the community and break down discrimination.

The findings suggest that the first priority should be to begin the process in schools to encourage children from an early age to be more understanding and accepting of people with mental health conditions. This in turn would facilitate the early uptake of

intervention services among young people. Some key question that still need to be addressed are: what the curriculum should look like; what the key messages should be; and whether the subject matter should constitute a separate course or be integrated as background material for traditional subject areas. There was no shortage of ideas from participants on how the task could be approached. More attention may also need to be focussed on addressing the use among school children of stigmatising language relating to mental health, and implementation of appropriate measures to curb this.

Most educators would readily acknowledge the importance of the parent-child relationship in influencing educational outcomes. However, it would seem that the profound impacts of parental mental health conditions on the emotional well-being of children and their capacity to learn may be less understood and may deserve more attention in the training of teachers. While there have been initiatives to introduce preventive and promotive mental health education into schools, there is a need to extend the scope of these programs beyond anti-bullying and building individual resilience, to specifically targeting and dismantling the social stigma associated with mental health problems. Such education is seen to be important in overcoming stigma and promoting help-seeking behaviour among young people.

Changing hearts and minds through the formal education process would also potentially influence the next generation of employers, journalists, film makers, writers and community members, paving the way for more positive attitudes and genuine social inclusion of people living with serious mental health conditions. In the words of one research participant, education at school could create a society that is “a little bit more

informed, a little bit more compassionate and a little bit more understanding.”

Education policy is also an important factor in bringing about culture change to overcome ignorance and increase awareness. This would need to include formal education in schools, as well as mental health content in tertiary education courses for key professions such as teachers ,lawyers, business management and health professionals.

The culture change suggested by participants needs to start with mental health professionals. Medical practitioners as well as other health professionals need training from undergraduate level to embrace a more positive recovery oriented approach to treatment of bipolar disorder and schizophrenia and their training should be informed by the lived experience of people with these disorders.

Employers generally lack awareness and understanding and are ill-equipped to manage people with these conditions effectively in the workplace. People living with psychotic conditions are well aware of and sensitive to employer prejudice and this often acts as a deterrent to them looking for work. Employers need information on what the risks are and skills to manage and mitigate risks in the workplace. Education was seen as an important means to overcome fear of the unknown and improve employer and co-worker attitudes.

**Education is not a panacea: need for exposure.** Participants pointed out that education and awareness alone is insufficient. We know from previous studies that mental health professionals, although perhaps the most knowledgeable about these conditions, may nevertheless display stigmatising attitudes and behaviours towards the mentally ill (Lauber, Braunschweig & Rossler, 2006). Until people are supported to

become fully functioning members of society, much of the mistrust and stigma towards mental health conditions will remain. In order to challenge existing stereotypes, the public needs to experience more frequent contact with people living and working in non-clinical settings and socially valued roles. This will provide opportunity for the public to experience their uniqueness and positive qualities as fellow humans, rather than as faceless members of a category to be feared. In order for these contacts to be positive, it is necessary that people be effectively treated and optimally supported to be successful in employment. In addition to education, exposure is needed so that people learn skills to interact with people living with these conditions. Other potential positive effects of exposure include greater understanding of the impacts of psychotic conditions, less concern about safety risks, and increase in capacity of the public to deal more sensitively with unusual behaviour.

**The exposure-disclosure dilemma.** Positive employment experiences would provide a powerful means to enhance public knowledge and understanding of these disorders as well as increase opportunity to challenge stigma and negative stereotypes. In mental health conditions, however, unless there is disclosure there is no exposure, and without exposure there can be no awareness. This reduces potential for social learning and attitudinal change.

Due to the fact that mental health conditions are usually less visible than physical conditions, personal disclosure of a condition would be required in order to increase community exposure to these conditions. Morgan et al. (2011) found that 56.2% of people with psychosis engaged in employment disclosed their condition to their

employer, thereby limiting opportunities for positive public exposure. Although generally recognised as very difficult and fraught with personal risks, participants felt that more disclosure by high functioning individuals is needed to reduce stigma. More disclosure in the context of positive employment outcomes may help to challenge the public mind-set and negative stereotypes that exist in the community. Conversely, integration of more people diagnosed with psychotic conditions into the workforce would help normalise it and overcome the need for disclosure. Employment would also potentially provide access to additional sources of emotional support and increase community knowledge, understanding and capacity to identify and respond early and appropriately in the event of deteriorating mental health. Inclusion of people with psychosis in the workforce may therefore directly contribute to changing community attitudes and workplace ethics in the direction of more tolerance, compassion and valuing of all workers.

**Need for effective treatment.** Responses in this study suggest unrealistic community expectations regarding the capability of medical science to effectively treat psychotic conditions. More research will be needed to improve medication and treatment effectiveness before congruence can be achieved between community expectations and the current efficacy of antipsychotic medication. Moreover, the current focus on early diagnosis and treatment of psychotic conditions is unlikely to improve employment outcomes unless there is simultaneously an expanded focus on recovery, including employment.

Sporadic but much-publicised public incidents leave an indelible impression on the public and perpetuate fear and stigma. Torrey (2011) has suggested that education in



itself is insufficient to reduce stigma and that *effective treatment* of psychosis is of primary importance to reduction of violence and hence stigma. Elbogen and Johnson (2009) found a strong link between psychosis, co-morbid substance misuse and violence, which suggests more assertive efforts are needed to address drug and alcohol issues in people living with psychosis. Co-morbid substance abuse or dependency, by predisposing to violent behaviour, thus plays a role in perpetuating negative stereotypes and social exclusion. Substance abuse or dependency also decreases employment outcomes, even among people *without* psychosis. The research literature indicates substance abuse is a cause as well as an effect or consequence of unemployment. This creates a vicious cycle in which the impacts of psychosis are compounded by the effects of substance abuse and unemployment (See Figure 64). The high incidence of co-morbid substance abuse among people with psychosis therefore requires more aggressive targeting and treatment.

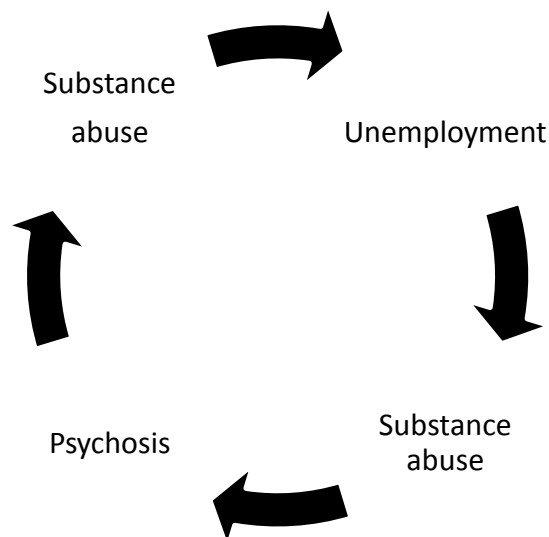


Figure 64. Interactive effects of unemployment, substance abuse and psychosis.

Recent efforts in Melbourne to co-locate disability employment services and drug and alcohol services seem to be a positive development (Cross, 2012). People with a severe mental health condition should be entitled to access evidence-based treatment such as motivational interviewing in order to address the high incidence of co-morbid substance dependency and/or to explore future options for work/study.

There is a need among mental health professionals as well as the general public for better understanding of the relationship between mental illness and violence and more community capacity for early detection of relapse and effective treatment. Available medications, while effective in reducing violence, have low compliance rates due to intolerable side-effects hence there is a need for more effective treatments and proactive treatment services. Psychological treatments for bipolar disorder and schizophrenia are still in their infancy and access to psychological treatment and support is subject to gate-keeping requirements. In terms of an Acceptance and Commitment Therapy (ACT) conceptualisation of psychosis, it could be postulated that behavioural activation towards valued goals, of which employment is a common goal, is key to improving emotional well-being and will increase vitality and alleviate negative symptoms

Greater access to motivational interviewing to address substance misuse and develop vocational goals is recommended. A more user-friendly system of specialist consultation is needed to avoid disrupting the working lives of people living with psychosis. Prevention of relapse is important for job maintenance and depends on the capacity of employees with psychosis and those around them to identify and respond appropriately to early signs of relapse.

**Recovery orientation.** A recovery orientation requires new ways of thinking about living with a mental health condition. A recovery orientated treatment service is required where treatment extends beyond symptom control to a positive focus on *flourishing*. An integral part of a recovery-oriented approach to treatment would include obtaining feedback to enhance performance in work-related situations. It can only be speculated whether a funding model for mental health services which is based on achievable measures of functional recovery such as employment would change the focus of treatment and remedy the current laissez faire approach to employment.

Responses from participants support the need for a major paradigm shift to educate health practitioners to support clients to work in spite of residual symptoms. There are also treatment myths which may stand in the way of recovery. For example, respondents endorsed the principle of early intervention, however, it is unlikely that more focus on diagnosis and treatment will improve social and occupational outcomes unless there is a concerted effort to address recovery goals *in addition* to medical treatment.

There is a need to refocus attention in mental health on the reciprocal relationship between work as a health outcome and health as a work outcome. In particular, there is a need for more education of mental health professionals regarding the importance and value of work. There is a need to provide training to clinicians in employment-related matters including assessment of work potential, employment service models and outcomes, and social security impacts of working. Evidence of the positive impacts of employment on clinical status suggests that investment in funding for skilled

employment support to enable people to obtain and retain employment would reduce the incidence of relapse and costs of re-hospitalisation.

**Improved self-management.** The recovery model requires changed thinking in which the client collaborates as an equal partner in treatment and shares responsibility for outcomes. In this model, rather than avoiding all potential sources of stress and being protected from failure, the client is supported to take measured risks. Failure is not seen as something to be avoided at all costs but as something that can be overcome and is necessary in developing resilience. More focus on improved client self-awareness and self-management of conditions would improve clinical and employment outcomes.

**More community services.** While the contemporary approach to physical health emphasises the importance of early intervention and primary prevention, community psychiatric services continue to prioritise risk management and crisis intervention, thus perpetuating the so-called revolving door. The history of custodial treatment as well as the current focus on compliance with pharmacological treatment as the mainstay of treatment has tended to foster dependency and place responsibility on medical professionals for achieving clinical and social outcomes. A notable exception in Australia has been the development of the National Youth Mental Health Foundation Headspace centres where early mental health intervention services are offered to people under the age of 25 years (Rickwood, Telford, Tanti, & Mc Gorry, 2014).

Participants in this study called for re-consideration of how funding is allocated for mental health services and urged more expenditure on improved community mental health services. The complex level of social and occupational disadvantage of people

living with psychosis (which includes a high incidence of unemployment, homelessness and incarceration) needs to be addressed with the appropriate level of funding for community services including employment support. There was also a need expressed for services to support people with psychosis living in the community. This includes improved accommodation options and transport services as well as home support services for those living at home and their carers.

There has been increasing recognition of the important role of family carers since de-institutionalisation. Participants in this study acknowledged the importance of family support in achieving employment outcomes. Carers may have far more influence over employment decisions than treating professionals. Many adults with psychotic conditions remain heavily reliant on family support and are influenced by the ideas and beliefs of carers about many issues including their employability and its possible impacts. There is a need to increase carer awareness of recovery principles, including the importance of satisfying employment to their caree's well-being and long-term security. Carers may be fearful, risk averse and/or unaware of the importance or therapeutic value of work in the overall management of major mental health conditions. Engagement of carers in evaluation of health and employment services would ensure services are more user-friendly for this group of job-seekers and that treatment service gaps are closed. It is important to stop blaming carers who, by default, were assigned responsibilities beyond their reasonable ability to cope. Dealing with people who are acutely unwell, even for professionally trained staff, may be "burdening and exhausting work" that can cause burn-out (Lauber et al., 2006). It was clear from this study that carers of people with

psychosis are subject to extreme stress in their role and that there is increased risk of family breakdown in these circumstances. There is a need to start providing more psycho-educational and effective emotional support for carers, as well as practical support in the form of community supports and services. More psychological support for carers would help to ensure quality care and retention of supportive family relationships critical to good health and employment outcomes. It is conceivable that employment may facilitate improved clinical outcomes by reducing the duration and intensity of interpersonal contacts at home and increasing tolerance of relatives. Practical as well as educational and emotional support for carers would contribute to improved family relationships, support and outcomes for people with psychosis, including improved employment outcomes. "Caring for the carer", that is maintaining the mental health of carers, is an essential pre-condition to maintaining healthy family relationships and the provision of quality care and support needed to sustain employment.

**Employer education.** It was felt that employers need to be made aware of the positive contribution that a person living with a psychotic disorder can make to the workplace. The question may be asked whether Australian workplaces, by consciously "screening out" mental disorder, are doing so at their own peril due to loss of positive attributes and qualities such as acceptance and respect (anti-bullying), empathy and compassion that can contribute to a more stable, diverse, happier and well-balanced workplace.

Some employers may be unwilling to accept this responsibility due to lack of understanding of the support needs of people working with psychotic conditions; and/or

lack of training and skills on ways to manage these employees so as to minimise any perceived risks to the business or unlawful behaviour in the workplace. Employers may unknowingly recruit people with psychotic conditions, as some people seek work independently of an employment service and may choose not to disclose their condition to an employer; therefore employers need skills to manage these employees if employment is to be sustained.

Education alone may also not be sufficient for employers who, although educated, may still not be willing to accept the risk. Three requirements were seen as essential for employers: a sympathetic attitude (positive personal qualities); suitable management training (knowledge and understanding); and financial incentives.

**Need for employer training and incentives.** Participants in this study considered that education and training is needed to enable employers to develop understanding, acceptance and insight. In addition, management training is needed to improve employer confidence in their ability to effectively manage business risks arising from any untoward workplace behaviour. Improved management training and directly accessible support for employers is needed to supplement the time-limited post-placement support currently provided by disability employment service providers.

To minimise risks of relapse, improve sustainability of employment and ensure the benefits of work are realised, training is essential for employers, managers and human resource personnel at all levels. Training is required to increase awareness, understanding and skills to provide effective workplace support and management of people working with psychotic conditions. Mental health first aid training for managers and workplace

first aid officers could play an important role in ensuring provision of appropriate crisis intervention if needed.

The need to ensure success of job placements is crucial to this process. Negative employment outcomes may deter future employment efforts on the part of jobseekers as well as employers. On the other hand, positive employment experiences are likely to increase employment opportunities and provide public exposure to positive role models with the opportunity to become de-sensitised and challenge negative stereotypes.

**Improved management practices.** Rather than being static variables, the stress of becoming unwell and stress of disclosure are dynamic variables that are subject to change in a more enlightened society. More awareness among employers and the need to improve workforce management skills to more effectively accommodate people living with a psychotic condition would be of benefit in improving the emotional climate for all workers. This would also enable behaviour towards this group to become more congruent with commonly upheld values in Australian society, which typically champions the cause of the “battler” or “underdog” and believes in a “fair go” for all. Exclusion from meaningful and socially valued roles is likely to engender despair, anger and vengeance and also increase substance abuse among otherwise placid and non-violent individuals, thus creating a self-fulfilling prophesy that people are aggressive and violent. Conversely, inclusion in meaningful and socially valued roles with appropriate support would generally enhance wellbeing and increase community capacity to respond to people who become acutely unwell, thus making for a safer society.



In order to realise the health benefits of work, people with mental health issues require healthy workplaces with good management practices. Rather than physical workplace adjustments, the adjustments that are required are attitudinal. Management practices require an awareness of the importance of the socio-emotional climate of the workplace, flexibility and responsiveness to the employment support needs of employees. The findings of this study suggest the need for increased awareness and understanding among employers, good management practises and willingness on the part of employers to accommodate episodic absences from work to ensure sustainable employment outcomes. The suggested changes in employment practices would benefit all workers through improvement in working climate and more inclusive, respectful and flexible workplaces. Management practices conducive to employment of people living with psychosis would ultimately be in the interests of *all* employees and should be a benchmark of good management practice. This would also increase the capacity of the community to manage these conditions effectively due to improved early detection and intervention, therefore reducing the need for re-hospitalisation.

**Increasing employment opportunities.** Arguably, the imperative to make a profit, inherent in our current economic system, may make discrimination inevitable due to the perceived risks to profitability for a company employing people with a serious mental health condition. Education alone may therefore be insufficient to overcome employer discrimination. Several respondents suggested the need for economic incentives for employers. Due to the increasing complexity and demand for productivity in the workplace, some legislative changes may be needed. These might include measures to

curb discrimination in the workplace, as well as the provision of incentives to employers to employ and retain the services of people with serious psychiatric disabilities. It was felt a system of ongoing incentives should be provided for employers due to insecurity associated with short-term wage subsidies and moral objection to the supported wage scheme, which allows employers to employ people with a mental health condition at below award wages. The current practice of employing people with severe mental health conditions at below award wages is morally questionable and could be replaced with a system where government subsidies enable people to be employed at or above award wages.

Respondents emphasised the need for flexible work options in regard to working hours and, if necessary, adaptation of the work role to suit the person. Participants considered that most people living with psychosis could work in competitive employment. However, several participants felt that alternative options should be available for those who might lack confidence or not be ready for the challenges of open employment. The concept of social firms was endorsed by participants, provided people are employed at or above award wages. This is consistent with the finding of the Burdekin report:

Any serious attempt to frame policies ensuring meaningful employment for Australians with psychiatric disabilities must, therefore, include a range of options. This does not mean, however, the return to the creation of a separate token workforce, relegating people with mental illness to menial jobs in a

protected environment. More imaginative (but practical) approaches are essential.  
(Rose et al., 1993)

There was little endorsement by respondents for short-term job placements and some respondents felt a need to access jobs which provide longer-term employment prospects. Non-government organisations would be well positioned to offer structured prevocational preparation courses, access to computer facilities to build computer literacy and opportunities for ongoing paid employment along the lines of social firms where people are employed at or above award wages. In contrast to previous approaches to prevocational support, there may be a need to develop more structured programs of prevocational support which have clearly defined goals and address some of the prevocational support needs identified in this study.

**Better integration of services.** It was apparent that more work needs to be done on the interface between mental health and employment services to achieve what one employment service provider described as, "being on the same page". Participants in this study highlighted the mutual benefits of improved communication among stakeholder groups involved in achieving employment outcomes. Participants articulated a need for better communication and collaboration between agencies whilst pointing out the lack of time and resources to arrange personal meetings with all stakeholders on an individual case basis. Australia has a well-developed information technology infrastructure which could be harnessed to promote more collaborative assessment, goals-setting and feedback among the different agencies providing care and support. Better use of information

technology would help to facilitate information sharing, progress recovery plans and provide relevant feedback and support to achieve employment outcomes.

More attention also needs to be given to meeting the prevocational and post-placement support needs of people living with psychotic conditions. These needs differ substantially from those of people who have an intellectual disability, where the main need is to provide extra support to learn the job. Many people living with psychotic conditions are socially isolated and disengaged from family and other support networks and therefore lack normal social supports essential to gaining and maintaining work. Increased availability of community support services and access to allied health support is needed to support people to succeed in employment. With the expansion of Access to Allied Psychological Services (ATAPS) program, the time may be ripe for more collaboration between private mental health professionals and employment service providers. In fluctuating conditions such as bipolar disorder and schizophrenia, it is crucial all stakeholders have ready access to current information about Job in Jeopardy assistance and support provisions around restoration of DSP, in order to allay fears of vulnerability in the event of relapse and give confidence to people to attempt work. In keeping with a recovery orientation, private psychologists could potentially play a more active role in facilitating return to work among people living with psychosis through assessment of prevocational needs, provision of work-focused psychological interventions and post-placement support. A more collaborative approach between clinicians and other stakeholders in the community would provide valuable feedback to

clinicians to better inform the approach to health care and provide needed perspective to counteract stereotypical notions arising from the “clinician’s illusion”.

**Assessments.** Assessments conducted by health professionals typically assume that work-related barriers lie predominantly within the individual in the form of symptoms. This thinking persists despite evidence of people with psychosis effectively working in spite of ongoing psychotic symptoms. There is a need to question whether the psychotic condition itself constitutes the main barrier to employment or rather the co-morbid conditions, treatment effects, individual characteristics and life circumstances that commonly accompany these conditions. Based on research evidence as well as comments of respondents it appears that co-morbid conditions, medication side-effects, individual qualities and life circumstances that accompany the condition may constitute more significant barriers to employment than the experience of psychosis itself. This thesis proposes that, while individual factors are important, most barriers to participation lie beyond the realm of symptoms, within the psychosocial context within which the individual lives and works. In contrast to the gloomy prognostications of previous eras, this thesis proposes that the various barriers to employment-individual, interpersonal and systemic-are all dynamic insofar as they are all subject to change. For example, employment barriers can be addressed through such diverse measures as improved self-management, addressing the person’s relationship with the condition, increasing public awareness and understanding, increasing work opportunities and improving employment support for people living with these conditions.

There is a need to broaden the focus of assessment to include workplace variables, including environmental factors such as emotional climate and type and level of support as important variables affecting employment outcomes. The ability to sustain work on a consistent basis may be more a function of the atmosphere and/or support provided to the worker in the workplace than of impacts of the condition itself. Although workplaces have become sophisticated in measuring the impacts of physical variables such as layout and temperature regulation, the impact of emotional climate in the workplace on work outcomes of employees living with psychosis have not yet been adequately explored.

**Employment services.** The most frequently referenced employment support need was for improved employment assistance. The findings of this study support the existing literature, which highlights the need to implement *effective* employment support practices for people living with psychosis. Twenty years after the publication of Burdekin report it is evident from participant responses that access to DES services remains problematic due to the inability of existing services to effectively service the employment support needs of people living with psychosis. This supports the call of Waghorn (2012) for employment services to implement more effective employment practices. The Individual Placement and Support Model (IPS) as an evidence-based model of service provision has failed to achieve widespread adherence to minimum standards of implementation in Australia. Better understanding of the failure to achieve compliance with this model may elucidate broader psychosocial barriers. While high fidelity employment support services based on the IPS model have demonstrated relative effectiveness at assisting jobseekers living with psychosis to *obtain* work, long-term employment outcomes have yet to be

clearly demonstrated. More support both internal and external to the workplace is needed to achieve sustainable outcomes. Certain negative aspects of the IPS model as currently implemented were highlighted by participants particularly the focus of rapid job placement, which may occur at the cost of a suitable job match and long term job retention. Motivation and improved self-management were identified as significant employment support needs which may not currently be receiving sufficient attention.

Participants in this study proposed that the employment of more people with lived experience of psychosis in employment services would improve understanding of employment support needs. It was suggested that increasing representation of people with lived experience in employment-related roles, as well as appropriate mental health training of all parties involved in provision of employment services, would help to achieve better employment, clinical and social outcomes.

Several participants referred to mistrust of government programs and services and indicated a preference for using non-government organisations. There was, however, a sense that non-government organisations may not offer *real* help in relation to employment and some participants appear to have adopted an alternative life-style around attendance at non-government organisations.

**Social security changes.** There was considerable agreement that deduction of payments soon after commencing work acts as a disincentive to working for many people. A possible solution to the dilemma of the so-called “benefits trap” might be to increase the income-free threshold and allow people on disability support pension to work and remain on DSP for longer before payment cancellation. This would enable

them to build self-confidence as well as experience the benefits of work before the DSP is cancelled. The additional cost of providing more social security incentives to work and study would likely be offset by reduced expenditure on health and hospital services due to the health benefits of work.

Participants in this study suggested many potential areas where intervention could improve employment outcomes for people living with psychosis including overcoming stigma, measures to improve motivation and self-management, and government policy changes. Due to the dynamic and interactive nature of barriers to employment it appears a broad-ranging approach to intervention would be needed. Measures that could be considered to overcome these multidirectional forces are shown, in no particular priority order, in Appendix N.

### **Limitations of study**

This study provides a snapshot of participants' perceptions and experiences that is relative to the time and place of the research and makes no claim to generalisability. The study involved participants living in metropolitan and regional areas of South East Queensland. A study of employment barriers and support needs in remote areas of Australia would help to highlight similarities and differences in barriers and support needs of people living in these areas. This study included relatively few respondents with low level educational attainment and in blue collar jobs. Future research investigating attitudes towards employment of people with psychosis should include a more representative sample in terms of education and socio-economic status. Only 8% of the



sample consisted of employers. Future studies should incorporate a broader range of different types of employers.

While an effort was made to include participants in the sample who were politically aware and active in mental health advocacy, it cannot be assumed that all participants in the sample were aware of the impacts of broader social structural influences such as economic and policies on their current experiences of reality. Although some participants alluded to socio/contextual issues, for example lack of available jobs even for people without psychosis and government agenda to maintain unemployment at a certain level, it cannot be assumed that participants were necessarily conscious of the impact of social structures and macroeconomic factors on the experience of jobseekers and employees living with psychosis.

Charmaz (2006) points out the need for qualitative researchers to analyse processes and actions in the data rather than confining the analysis to topics and themes. The analytic depth of the current research could have been improved by embedding more actions and processes into the codes.

### **Comparison with previous research findings**

The findings of this study build on the work of Larson et al. (2007). In addition to investigating perspectives of individuals with psychiatric disabilities on the benefits and costs of employment, this study has also considered the perspectives of other stakeholder groups on the cost-benefits of employment and unemployment. The current study confirmed the importance of many of the individual benefits identified by Larson et al. and in addition revealed community benefits.

This study supports the finding of Henry and Lucca (2004) that stigma constitutes a significant barrier to employment for people living with psychosis. Consistent with literature on stigma there was also evidence in the present study of stereotyped notions of dangerousness, unreliability and unpredictability. In addition, some employment-related stereotypes were identified such as more litigious, less productive, and having a higher absenteeism rate.

This study confirmed the findings of Marwaha et al. (2009) that health professionals are typically concerned that stress associated with employment may precipitate relapse, and lack resources and relevant knowledge to facilitate employment outcomes. This study supports the finding of other researchers that aspects of the social security system, including lack of understanding of financial impacts of work, can act as barriers to work (Tse & Yeats, 2002). It also identified a lack of awareness among participants of measures to promote employment outcomes such as job in jeopardy support and special provisions to facilitate rapid restoration of DSP in the event of job failure. The study also identified significant gaps in clinician knowledge of employment service provider services and capacity, work capacity assessments, outcomes of work-related referrals and impacts of employment on social security benefits. This supports the recommendation of Marwaha et al. (2009) of more training of clinicians in employment-related issues. The findings also support those of Crawley et al. (2007) and King et al. (2011) that health professionals need more information and resources to assist their patients to access employment services. The present study identified that carers also need more resources on employment support services.

Tse and Yeats (2002) found that in addition to individual factors, broader social contextual factors are important determinants of employment outcomes in psychosis. The present study supported the view that there are multiple factors that influence employment outcomes among people living with psychosis including individual factors; aspects of the psychosocial environment such as attitudes, perceptions, beliefs and expectations of significant others; and systemic barriers. Findings of the present study also suggest that there is a complex and dynamic interaction among these multiple factors, which is shown schematically in Figure 65. Both studies identified the importance of maintaining a sense of hope and that improved self-determination can assist people to attain their vocational goals.

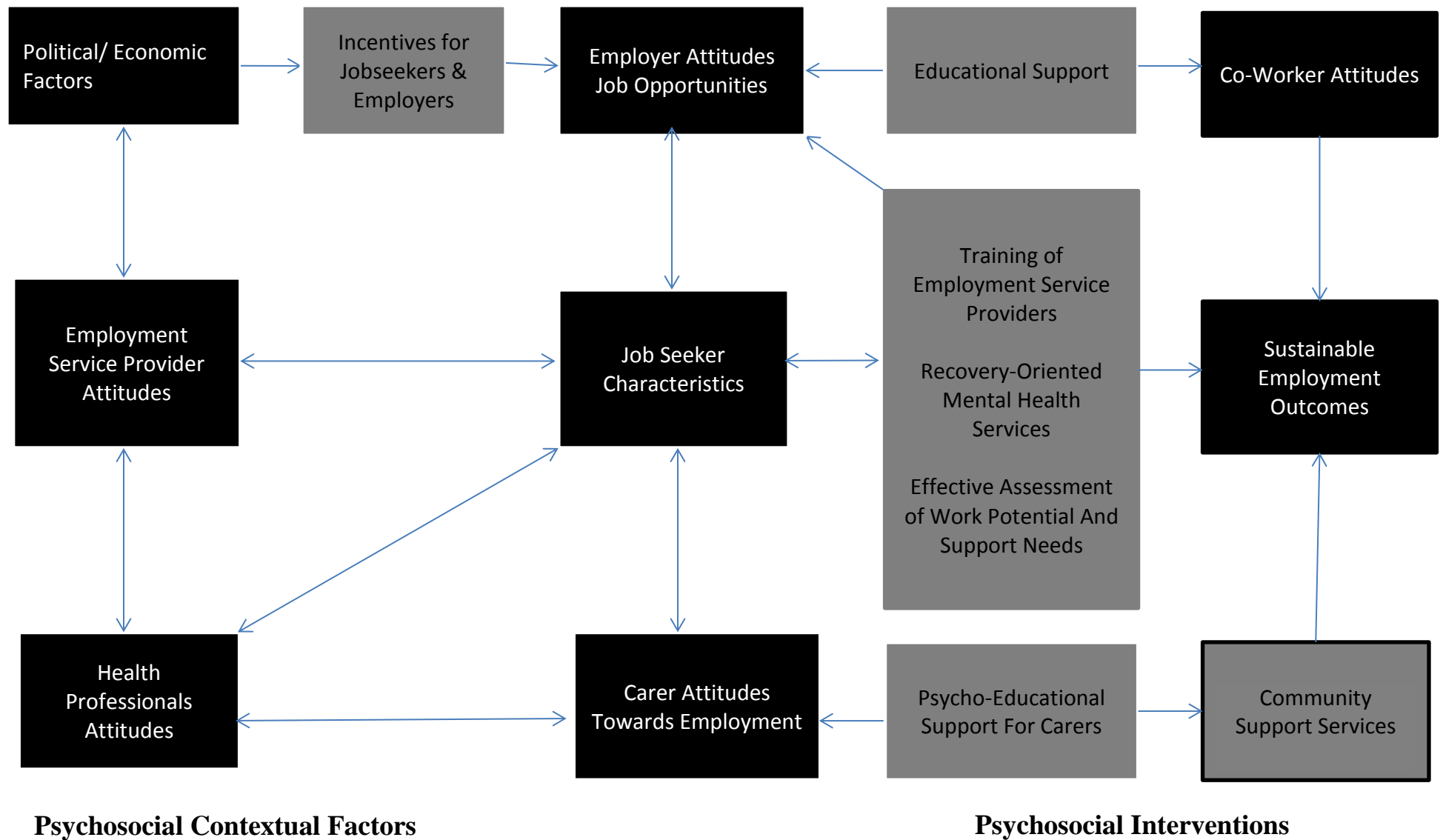


Figure 65. Multidimensional Model: Psychosocial Factors Affecting Employment Outcomes in Psychosis: Towards an Integrated Approach

The findings also support the ICF model of participation by identifying that, in addition to factors inherent in the mental health condition itself, there are important personal and environmental factors affecting employment outcomes among people living with psychosis. The findings on the benefits of employment for mental health also lend support for the ICF conceptualisation that there is a dynamic and reciprocal relationship between participation and the mental health condition, in other words, that personal and environmental factors impact participation and activity, which in turn impact the mental health condition. (See Appendix B).

The research literature suggests that not all work is good work and that in order for the health benefits of work to be realised, the work undertaken must be “good” work. This study has shed light on some variables which may be associated with “good” work. Examples include a good fit between the person and the role; realistic and meaningful work where the demands do not exceed the person’s physical and emotional capacity; good management, and supportive work mates.

### **Future Research**

More research is needed on psychosis and work to determine inter alia whether and to what extent employees living with serious mental illnesses have increased rates of absenteeism, work-related compensation claims and litigation. Many employer concerns about the impacts of psychosis in the workplace remain unanswerable due to lack of objective data on the work behaviour of employees with psychosis, including absenteeism and litigation rates in comparison to the general population. More rigorous research is needed on *actual* work performance indices, in order to realistically inform

employers of risks and potentially challenge the speculative ideas and stereotypes that currently exist. There is a paucity of research on the incidence of workplace violence associated with psychosis and the likelihood of its occurrence relative to other adverse incidents in the workplace. There is also a lack of knowledge on the workplace variables likely to mediate this relationship. In the absence of accurate data, it is impossible to accurately and objectively predict employment risks. Participants in this study alluded to the debilitating side-effects of anti-psychotic medication on work ability and identified need for funding of research to find more effective medications for psychotic disorders.

Respondents indicated that employment outcomes for people with major mental health conditions may be influenced by clinical factors such as severity of condition and cognitive symptoms. The reverse proposition that employment is a predictor of clinical course in psychotic disorders has not yet been rigorously explored. Similarly, there is need for more longitudinal studies to determine whether employment is a predictor of improved cognitive functioning rather than vice versa. There is also a need for more studies to investigate whether cognitive decline in psychosis is a function of social isolation, lack of meaningful stimulation and unemployment rather than an intrinsic aspect of the condition itself.

Future studies of the effectiveness of Individual Placement and Support (IPS) model in the Australian context should focus on understanding why the 40-60 % of people engaged in high fidelity IPS services still do not obtain employment. This would help to elucidate factors within and beyond the employment service model that still need to be addressed to improve employment outcomes for people living with psychosis.

Research should also aim to improve understanding of motivational deficits in psychosis, and investigate psychological interventions to increase motivation to engage with employment services, and to achieve work, study and social outcomes.

People with personal experience of a mental health condition, including their carers and families, have access to a body of knowledge that is inaccessible to those not sharing this experience. There is need for more research into the subjective experiences of people living with psychosis and their carers. There is a need for more research projects in the area of mental health recovery and to develop recovery-orientated research methods in which people with lived experience and their carers work collaboratively with researchers to frame the research questions and give voice to their lived experiences.

Future research should examine why people with psychosis who have obtained employment subsequently drop out of employment and the workplace variables impacting on employment outcomes. Participants in this study pointed out that work that is meaningless or exploitative is not beneficial. There is a need to define more clearly what constitutes “adequate” or “good” work for people generally, and more specifically for people living with psychosis. There is also a need to explore the subjective experiences of people working in social firms to explore the potential benefits and limitations of this approach in the Australian context.

### **Concluding Remarks**

Since the process of de-institutionalisation commenced in Australia, attention has been given to community treatment and housing issues for people living with psychosis. However, there is still much that remains to be done before erstwhile mental hospital

patients reclaim full citizenship rights in society, which includes the right to paid employment at award wages. Although a well developed infrastructure of employment services exists in Australia and there has been growing interest in recent years in improving employment services for people living with psychosis, rates of competitive employment remain very low at around 21.5% (Morgan et al., 2011). The findings of the present study suggest that the current focus on individual treatment and rehabilitation is unlikely to significantly improve employment rates without attention to broader interpersonal and systemic issues. Likewise, adjustments to employment service provision alone are unlikely to result in significant change in the rate of sustainable employment of this cohort. Indeed it may also be necessary to re-focus concerns about individual work capacity to broader contextual issues to determine who exactly needs to be ‘work-ready’: the client, the carer, the treating health professional, the employment service provider, the employer, or the community.

Concern has been expressed that in advocating the value and importance of work, some people with severe mental health conditions may feel de-valued if they do not work. It must be emphasised that people are intrinsically valuable even if they can not work. Many perform unrecognised yet valued roles in their family or as carers. Indeed some would argue that people have a right *not* to work if meaningful work is not available to them. Nevertheless, it is a reality that in contemporary Western society one’s value and sense of personal identity are intimately related to one’s employment status.

This research highlights a contradiction between the generally accepted social values in Australian society of egalitarianism and inclusiveness, and current societal



attitudes and behaviour towards the employment of people living with a psychotic condition. Greater awareness and understanding of the complexities of this response may hopefully motivate positive change and bring about more congruence between our generally upheld values as a society and our actual work-related attitudes and behaviours.

The low rate of competitive employment among people living with psychosis constitutes a major barrier to social inclusion. Engagement in employment could potentially overcome social isolation, provide increased social support and increase community capacity to respond appropriately to changes in mental status, making the management of psychosis safer for both the individual and society.

The findings of this study highlight the fact that, twenty years after the release of the Burdekin report, there is still unfinished business to be done in Australia to improve employment outcomes for people living with psychosis and realise The Universal Declaration of Human Rights (United Nations, 1948) Article 23 that “Everyone has the right to work, to free choice of employment, to just and favourable conditions of work and to protection against unemployment”. Social and vocational integration into meaningful forms of activity including employment is not only essential from a social justice perspective but could also be an essential means to promote recovery.

### **Summary and Conclusion**

By engaging multiple key stakeholder groups, this qualitative study has provided a broad and comprehensive view of employment barriers and support needs of people living with psychosis. The study found that employment barriers for people living with psychosis are multiple and diverse including individual, interpersonal and systemic

factors. Although participants reported many challenges associated with managing psychotic conditions, no client participant considered the condition itself to be an insurmountable barrier to employment. The most frequently referenced employment barriers in this study were interpersonal barriers in the form of community knowledge gaps, public stigma and discrimination against people living with psychosis. Systemic barriers across several areas of government policy including mental health, employment, social security and education were also found to play an important role.

Importantly, the present study found that many barriers are dynamic and therefore subject to change. Support needs identified require a broad-ranging approach to intervention that extends beyond treatment of the individual to include psychosocial and systemic changes. The employment support needs most frequently voiced were for more effective assistance to gain and maintain employment. The process of employment service provision is only one aspect of a much broader picture that needs to be addressed, as many people currently do not use employment services due to low expectations and the stigma associated with disclosure. Wide-ranging systemic changes are required if employment rates are to be improved among people living with psychotic conditions. Findings of this study suggest that more attention to overcoming psychosocial barriers to employment could result in significant improvement in the employment rate and thereby social inclusion of people living with psychotic conditions.

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## Appendix A

*Differences Between Traditional Medical Model and Recovery Model*

	Traditional medical model	Recovery model
Paradigm	Biological Reductionism	Focus on personal and societal growth and development
Conceptualisation	Illness	Symptoms represent variation on continuum of normal human experience
Aetiology	Biological explanation e.g. genetic, biochemical	Usually precipitated by extreme stressor/traumatic experience
Goal of treatment	Eradication of symptoms	People should be supported to accept symptoms and establish a comfortable relationship with them
Prognosis	Permanent and incurable with cognitive deterioration Recovery is not possible cf. Kraepelin	People can live a valued and meaningful life in spite of symptoms
Phenomenology	Focus is on negative experiences and deficits; disability  Meaning of symptoms in psychosis is irrelevant to treatment	Some voices are positive and may serve a positive psychological function; focus on ability  Understanding the meaning of symptoms in psychosis is crucial to understanding and effective treatment (May, R)
Treatment Model	Pharmacological; may include hospitalisation and involuntary treatment	Acceptance model (ACT) Existential model-some may wish to explore meaning of experience Phenomenological model Client-centred (client leads

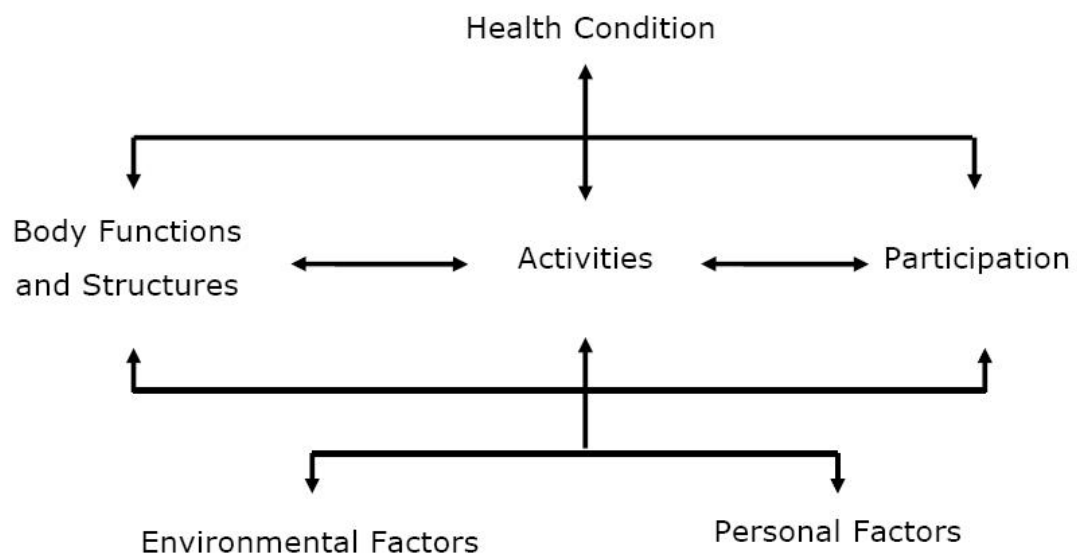


		the way). CBT focussing on improving self-management of symptoms.
Treatment stakeholders	Medical personnel; patient; Law enforcement	Consumers have a central role in their own recovery. Society has responsibility to reduce stigma (media), provide opportunities and necessary support
Role of individual	Patient consumer. Sick role requires patient to be a passive and compliant and is usually less powerful in decision-making.	Must actively work towards own recovery and work towards becoming an active participant in society
Psychosocial outcomes	Clinical features predictor/determine psychosocial outcomes. It is often assumed that effective symptom control will improve wellbeing and result in improved psychosocial outcomes.	Life experiences can modify clinical outcomes. Symptom control alone does not necessarily result in better psychosocial outcomes. Improved wellbeing, regardless of continuing symptoms, can contribute to reduction in symptoms or severity (Davidson, 2006 b in Craze p22)
Aim of Services	Hospital and clinic-based services to manage treatment and relapses. Focus of services is on treatment adherence; risk management and crisis intervention	Aim is to improve self-management, recognise and maximise potential, overcome avoidance and increase resilience. Consultation-liaison services aim to maintain wellness by increasing community awareness and support; reduce stigma and increase community capacity to identify and response appropriately to early signs of relapse.

Knowledge	Medical, nursing and allied health professional hold specialised (elitist) knowledge which is not readily accessible to the public	People with lived experience are considered experts by experience. Mental health care professionals work collaboratively with those with lived experience, family, carers and other stakeholders in the community to improve mental health literacy, social and vocational outcomes.
Expectations	Expectations are lowered and people are protected from the presumed stress of participation.	People should be supported to lead a meaningful and contributing life and be active citizens within the community.
View of Work	Employment is seen as a potential source of stress which should be avoided to prevent relapse. Extended periods of work avoidance and non-participation are enabled through sick certificates.	People are actively encouraged to maximise their potential for paid or unpaid work. People are encouraged to access programs of support to return to work as soon as possible following a relapse. Work provides distraction from symptoms, stimulation and opportunity to develop skills, abilities and self-confidence.
View of risk taking	Risk averse. Seeks to eliminate risk. Relapse to be avoided at all costs.	Supports positive risk-taking and the dignity of risk. (Slade in Craze review p.28) Relapse is viewed as an inevitable part of recovery.

## Appendix B

The International Classification of Functioning, Disability and Health (ICF), (WHO, 2001)



## Appendix C

**Client Semi-Structured Interview****Appreciative Enquiry**

How long have you been a member at Clubhouse?

How did you find out about Clubhouse?

What are the benefits of being a member?

What do you value the most about being a member here?

What are your future goals?

What do you see as your main obstacles to getting paid work?

Have you worked in any form of paid employment in the past?

**Barriers**

**We know that many people who have been diagnosed with schizophrenia or bipolar disorder would like to work in regular paid employment. We also know that the employment rate of people with these conditions is significantly lower than the general population. Why do you think this is the case?**

*Motivation to work*

What are the factors that affect your motivation to work?

What are the good things about working?

What are some of the less good things about working?

During times that you have been unemployed, how did that affected you?

Do social security benefits affect your decisions about work?

What has been the approach of health professionals towards work/study? Do you think this is the right approach?

*Jobseeking*

Have you experienced any barriers due to your condition whilst looking for work?

Have you ever experienced any form of discrimination while job-seeking? How have you dealt with it?

*Work/Study*

Does your condition affect your ability to work in any way? (Either positively or negatively)

How do/did you deal with this?

Does your condition affect your ability to study in any way?

Does medication affect your ability to work/study?

Does your condition affect your ability to drive or use public transport?

How do you get to work?

What challenges have you faced in a work situation as a result of your condition?

What has been your experience with employers? (Explore attitude, understanding and behaviours of employers)

What has been your experience with co-workers (Explore attitude, understanding and behaviours of employers)

Have you ever experienced discrimination while in employment? How have you dealt with it?

Do you think working affects your mental health in any way?

How does your mental health during periods of employment compare with your mental health during periods when you are unemployed?

*Adverse Work Conditions*

When things were not going so well at work what was happening?

What sort of work environment do you find difficult?

What work circumstances do you find unfavourable i.e. aggravates your condition?

Are there work situations that you would find particularly difficult or stressful?

Why did you leave your most recent/previous jobs?

Why did you leave the consumer consultant position?

What has been your experience of returning to work following a period of unwellness?

What support has been available to assist you to return to work?

### **Support Needs**

**What do you think would need to change in order to improve employment outcomes for people who have been diagnosed with schizophrenia or bipolar disorder?**

#### *Positive work conditions*

Has the work you have done in the past been your preferred type of work?

If not, what kind of work would you like to do? What prevents you from doing this work?

What sort of work environment do you prefer?

Describe the best work situation you have ever been in. Why was it so good?

What personal qualities enabled you to achieve this success?

What supports around you enabled you to experience success?

When things were going really well what was different?

What helps you to succeed at study/work?

How important has family support been for success at study/work?

#### *Disclosure*

How important is it for you to tell your employer about your mental health condition?

What do employers need to know about your condition?

Have you ever disclosed your condition to an employer?

How did you do it? How did he/she react? How did you feel about it afterwards?

When do you feel you should tell your employer about your mental health condition?

What is the best way to disclose this information?

Do you think employers need any type of support?

#### *Employment Support Provision*

Have you ever used the services of an employment service provider?

What has been your experience with employment service providers?

What type of employment support do/would you value the most?

Would you prefer to use a mainstream ESP or a disability-specific ESP?

Would you prefer to use HR support services provided by the company, or employment support services provided by an external employment service?

What sort of background would you prefer in an ESP? What qualifications would be desirable in an ESP?

Do you think employment services providers should employ qualified mental health professionals?

What personal qualities do you value in an employment service provider?

What do you think about employment service providers engaging peer support workers?

Are there any workplace adjustments you have found/ would find helpful?

What type of employment support or adjustments have/would you value the most from your employer?

What other types of support would be helpful to you in obtaining and/or maintaining employment?

*Coping Strategies & Supports*

Have you ever been given advice /support on how to manage your condition in the workplace? From who? What did they tell you to do?

What strategies do/have you used to cope with symptoms at work? How helpful have they been?

Does your doctor ever talk to you about work? How often? What is his/her attitude re work?

Does your family talk to you about work? What do they think about you working? Why?

Who is the best people/organisation to support people back into work following a period of absence from the workforce due to unwellness?

Do you think that employment of more people with schizophrenia or bipolar disorder would increase awareness and understanding of these conditions in the community?

Do you think more people need to come out of the closet so to speak?

Based on your work experiences, what have been your main learnings in relation to managing your work life? What wisdom can you share with others living with bipolar disorder/schizophrenia who are starting out on their career or working life?

Miracle question

Is there anything else you would like to add on this subject that we haven't already covered?



## Appendix D

### **Carer Semi-Structured Individual Interview**

#### **Appreciative Enquiry**

You have previously told me that your [relative] has been diagnosed with schizophrenia that that on one occasion you presented an educational opportunity to a class of school children to learn about schizophrenia. Can you explain to me what you did?

What inspired you to do that?

What personal qualities enabled you to do that?

What other supports around you enabled you to do that?

How did the children react?

How did the teacher react?

How did the parents react?

How did your brother react?

#### **Barriers**

**We know that many people who have been diagnosed with schizophrenia or bipolar disorder would like to work in regular paid employment. We also know that the employment rate of people with these conditions is significantly lower than the general population. Why do you think this is the case?**

#### *Attitudes*

What do you see as the main barriers to employment for people who have been diagnosed with schizophrenia?

Do you consider competitive open employment to be a realistic goal for people living with schizophrenia?

Has your [relative] ever worked in mainstream employment?

What are your thoughts/feelings about your [relative] entering or re-entering employment?

What would be your main concerns about your [relative] working in open competitive employment?

#### *Past experiences*

What barriers to employment have you observed as a result of his condition?

What have you observed in relation to his experience of job-seeking?

What have you observed in regard to his experience of employment?

Has there been any experience of discrimination or workplace harassment?

*Impacts of Condition*

What do you consider to be the main work-related impacts of his condition?

Are there any impacts on driving or ability to use public transport?

Would there be any occupational health and safety concerns?

*Perceived Impacts of Work*

What impact does work/unemployment have on your [relative's] health and well-being?

How does this compare with his health and well-being during periods of unemployment?

Do you think social security payments affect decisions about working? How?

How would it affect you if your [relative] returned to work?

Impacts of language “mental health”, schizophrenia

Are there any other barriers we have not already discussed?

**Support Needs**

**What do you think would need to change in order to improve employment outcomes for people who have been diagnosed with schizophrenia or bipolar disorder?**

*Jobseeking*

What kinds of support/assistance would it take for your [relative] to *obtain* competitive employment?

What would it take for your [relative] to be able to successfully *maintain* employment?

What has been your experience of the assistance provided by disability employment services?

What has been your experience of [social security agency] in assisting your [relative] into work?

What has been your experience of health professionals in regard to supporting work outcomes?

What do you think would increase motivation to work among people with schizophrenia?

What are your thoughts on the supported wage scheme?

(The Supported Wage System is a process that allows an employer to employ a person with a disability and pay them at less than the award wage based on an assessment of their productivity.)

*Support to maintain work*

What do you think would increase work capacity in people who have been diagnosed with schizophrenia?

What reactions have you observed when your [relative] commences a new job? How did you respond to this?

What types of support/assistance would be required to *maintain* competitive employment?

What type of return to work assistance has been available during periods of relapse?

It has been said that the level of care required by someone with schizophrenia to enable them to be successful in employment can be likened to the support required by an elite athlete. What are your views on this statement?

What type of additional care/support has your [relative] needed during periods when she has been working?

Do you think people with schizophrenia who are job-seeking or working still need a carer? For what types of reasons?

Have you identified any other unmet employment support needs?

#### *Work environment*

Is your [relative] doing his preferred type of work/activity? If not, why?

What sort of work environment do you think he would prefer?

What sort of work adjustments/accommodations would be helpful?

What type of stressors would he find most difficult to cope with at work?

What factors in the workplace do you think most affect employment outcome?

What are your thoughts on disclosure?

Do you think the employment of more people with a mental health condition would impact on social stigma in any way?

Have there been any positive work-related experiences? What was different?

Have there been any good news stories along the way?

Do you have any other comments about this subject that have not already been covered?

## **Appendix E**

### **Health Professional Semi-Structured Interview**

#### **Appreciative Enquiry**

Do you have any success stories?

What values on your part enabled this outcome?

What personal strengths did you draw on?

Were there others involved in achieving this outcome?

What are the key ingredients that make the current employment service model successful?

#### **Question 1**

**We know that many people who have been diagnosed with schizophrenia or bipolar disorder would like to work in regular paid employment. We also know that the employment rate of people with these conditions is significantly lower than the general population. Why do you think this is the case?**

#### **Barriers**

What are the main barriers to employment for people diagnosed with schizophrenia or bipolar disorder?

What has been your experience of people with a serious mental health condition entering competitive employment?

What factors may influence employment decisions in this group?

What factors might affect employment outcomes?

What impact does medication have on ability to work?

The fatigue that clients experience when returning to work is that likely to be due to work hardening or drug effects?

What has been your experience of carers in relation to encouraging their family members to work?

Do you think health professionals are sufficiently informed about evidence-based best practice in the area of employment of people with schizophrenia or bipolar disorder?

Have you received any training in evidence-based best practice in the area of employment of people with schizophrenia or bipolar disorder?

Do you think there would be any value in this training?

What factors might affect motivation to work?

Are there aspects of the system that are disabling in relation to employment?

Does the social security system affect employment outcomes?

Some people prefer not to accept the offer of extra work hours if it means losing DSP. What factors might be involved here?

### *Attitudes & Expectations*

Do you think entering open competitive employment is a realistic goal for people living with a serious mental health condition such as schizophrenia or bipolar disorder?

Are there consumers who, in your opinion, would not be capable of working in mainstream employment?

Are there any attitudes or mind-sets that may need to be challenged in order to improve employment outcomes among people diagnosed with a serious mental illness?

Are clinicians over-protective? Are we reinforcing dependence and avoidance?

Can resilience be built without exposure?

What would be your estimate of the percentage of patients with schizophrenia or bipolar disorder who would like to work?

Health professionals often consider employment as "too stressful" for people with serious mental health conditions. What are your views on this?

In your opinion what percentage of these patients is likely to obtain work in open employment?

In your opinion what percentage of these patients is likely to maintain open employment for more than six months?

What is your understanding of "recovery" in the context of schizophrenia or bipolar disorder?

Language-is the term "consumer" consistent with a recovery approach?

How important do you consider employment in recovery from serious mental illness?

How important do you consider employment to be in the overall management of bipolar disorder and schizophrenia?

How often do you discuss employment during treatment sessions with patients with schizophrenia or bipolar disorder?

How much time would you spend discussing employment with clients during sessions?

Who would usually initiate these discussions?

Do you consider employment outcomes to be part of your role/responsibility?

Do you consider it part of your role as a treating health professional to refer patients with a serious mental condition to disability employment providers?

### *Views on Benefits & Drawbacks of Work*

How do your patients usually experience employment?

What do you consider the main benefits (if any) of employment for people diagnosed with a serious mental health condition?

Are there any disadvantages or negative impacts of work?

What would your main concerns be about people with a serious mental illness entering competitive employment?

Do you think employment could have destabilising effect on a patient's condition? What factors might be involved here?

What impacts do you think employment of persons with a serious mental health condition could have on community safety?

In your experience how does employment impact on the clinical course of serious mental health conditions such as schizophrenia or bipolar disorder?

Do you consider the benefits of employment outweigh the possible negative impacts in clients with a serious mental health condition or vice versa?

What feedback have you received from patients with schizophrenia or bipolar disorder on their work-related experiences?

### *Assessment*

How would you determine work-readiness in a person with a diagnosis of schizophrenia or bipolar disorder?

What are your views on the job capacity assessment process?

Are there any issues around JCA assessments?

Should best practice model include cognitive assessment?

How long would you recommend that a person wait following an acute psychotic episode, before trying to return to work in paid open employment?

Does a person need to be symptom-free before they can work?

Do you think that someone with ongoing psychotic symptoms should be encouraged to work in spite of ongoing symptoms?

### *Integration of Services*

It has been said that people with a serious mental health condition often "fall through the cracks" when it comes to employment. Why do you think this occurs? At what stage would this tend to occur?

Not everyone gets a case manager. What form of health follow-up is there for remaining clients? What opportunities exist to engage them with the employment system?

Who is responsible for employment outcomes among in-patients? How much priority is currently placed on employment ?

Currently are employment outcomes among out-patients measured or monitored in any way?

What has been your experience in regard to the integration of services related to employment?

Have there been any challenges in referring clients for employment support?

## **Question 2**

**What do you think would need to change in order to improve employment outcomes for people who have been diagnosed with schizophrenia or bipolar disorder?**

**Support Needs**

What would it take for more patients with a serious mental illness to successfully work in open employment?

How would you respond to a patient seeking guidance about disclosure of his condition to an employer?

What would enhance work-readiness in persons with a serious mental illness?

What would increase motivation to work among clients with a serious mental health condition?

What changes need to occur to improve employment outcomes?

What changes need to occur in order for more clients with a serious mental illness to obtain employment?

What needs to change if more clients with a serious mental illness are to maintain employment?

What psychotherapeutic approach/es would you consider hold most promise in relation to the provision of employment support for people with a serious mental health condition?

What in your experience has worked well?

What has worked less well?

How could existing services be enhanced to improve employment outcomes?

Could psychologists play a more active role in improving employment outcomes? How?

Is there a need to change the way psychological services are structured/delivered in the community? Are psychologists in the right places?

How could health system/health professionals better support people with schizophrenia or bipolar disorder to return to work?

Do you think there are any changes to the social security system that could improve employment outcomes?

Would managing transition to work on health end reduce risk of inappropriate placement /poor outcomes that could occur if client self-initiates the process without adequate support?

What about people who have been out of the workforce for a long time?

*Disability Employment Services*

Do you think VOR or ESS is a better employment support option for consumers with a serious mental health condition such as schizophrenia or bipolar disorder?

What are current contract arrangements with DES providers?

How are contracts arranged with DES providers?

How is communication with other providers managed?

Are there any changes needed to the way in which employment services are provided for people diagnosed with a serious mental health condition such as schizophrenia or bipolar disorder?

Have you been contacted by a disability employment provider during the past year?

How accessible is information about employment services to clients and health personnel?

Are you aware of mobility allowance the job in jeopardy program?

Have you referred any of your patients to a vocational rehabilitation service?

Have you referred any of your patients to a disability employment service?

What means of information sharing with specialist disability employment providers would be most valued?

What has been your experience of relationships/co-ordination between organisations offering employment services?

What feedback have you had from patients regarding the effectiveness of disability employment services?

What type of staff do you think DES providers should be employing?

Do you think employment services should engage peer support workers?



## Appendix F

### Employment Consultant Semi-Structured Interview

#### Question 1

**We know that many people who have been diagnosed with schizophrenia or bipolar disorder would like to work in regular paid employment. We also know that the employment rate of people with these conditions is significantly lower than the general population. Why do you think this is the case?**

What do you consider the main benefits of employment for persons with a serious mental illness?

What are your main concerns about people with a serious mental illness entering competitive employment?

What factors affect motivation to work in clients with a serious mental illness?

Do you think entering open competitive employment is a realistic goal for all people living with a serious mental health condition?

What is the best approach to assisting people living with a serious mental health condition who has been out of the workforce for a long time?

If a client with a serious mental health condition contacted your service what contact, if any, would you initiate with their doctor/case manager and what how would you manage this process?

What has been your experience of information-sharing with public health system?

What are your views on current processes?

JCA hour band-widths-are they obligated to restrict work hours to those recommended in the JCA report?

What have been your experience of the main issues facing people with a serious mental health condition entering competitive employment?

Approach to disclosure

What is working well?

What has not worked so well?

What factors in the workplace might affect employment outcomes?

What other factors may influence employment decision/outcomes in this group?

Do social security payments affect work decisions?

Are there any other barriers to employment?

#### Question 2

**What do you think would need to change in order to improve employment outcomes for people who have been diagnosed with schizophrenia or bipolar disorder?**

What needs to change if more clients with a serious mental illness are to obtain employment?

What needs to change if more clients with a serious mental illness are to sustain employment?

What kinds of employment support/assistance would improve ability to obtain employment?

What kinds of employment support/assistance would improve ability to maintain employment?

How do you determine work-readiness?

What do you think about ESPs engaging peer support workers i.e. people with a lived experience of a mental health condition?

Do you think health professionals employed by the service could add value?

Mainstream vs. specialised services?

What type of training needs exist?

Would you discourage a person on DSP from working more than fifteen hours per week?

What is it that motivates you in this role?

Are there any other changes needed?

Describe a time when you felt really proud of the work you did in assisting a person into employment

What values on your part enabled this outcome?

What personal strengths did you draw on?

Were there others involved in achieving this outcome?

Is there anything you would like to add?

## Appendix G

### Employer Semi-Structured Interview

**We know that many people who have been diagnosed with schizophrenia or bipolar disorder would like to work in regular paid employment. We also know that the employment rate of people with these conditions is significantly lower than the general population. Why do you think this is the case?**

Have you had any experience in relation to employment of people with schizophrenia or bipolar disorder?

Do you know of anyone other employer who has employed people with these conditions?

Do you have any positive experiences to share?

What values on your part enabled this outcome?

What personal qualities on your part enabled this outcome?

Were there others involved in achieving this outcome?

During your business career have you ever been provided with education or training on management of people with these conditions in the workplace?

If no, do you think this type of training would have been helpful to you?

Have you ever worked alongside a person with one of these conditions?

What do you think are the main challenges to be faced when employing people with schizophrenia or bipolar disorder?

What impacts would you expect there to be on co-workers?

What would be your main concerns about employing someone with a mental health condition?

Are there any legal concerns?

Do you think there would be any other risks?

What do you think about the supported wage scheme?

Do you think social security payments/arrangements affect decisions about work?

### SUPPORT NEEDS

**What do you think would need to change in order to improve employment outcomes for people who have been diagnosed with schizophrenia or bipolar disorder?**

What would need to change to make more employers willing to employ people with bipolar disorder or schizophrenia?

Is any form of legislation needed to improve employment opportunities for people with these conditions?

Do you think incentives would be required? What type of incentives would you recommend?

What type of workplace adjustments do you think would be required?

If you were to knowingly employ a person with schizophrenia or bipolar disorder what would you need to know in order to adequately support them in the workplace?

Are there any gaps in the support provided to employers?

Do you think adequate support is available to assist people to return to work following periods of relapse?

What additional supports would be helpful?

Is there any education/training that should be provided to employers around employment of people with these conditions?

Are there any attitudes that need to change?

What rewards might there be?

Based on your experience what advice would you give other employers in regard to employing people with bipolar disorder/schizophrenia?

What about social firms?

Are there any questions I should have asked you that I didn't?

Is there anything else you would like to add?

## Appendix H

### Semi-Structured Interview: Community Member

#### Question 1

**We know that many people who have been diagnosed with schizophrenia or bipolar disorder would like to work in regular paid employment. We also know that the employment rate of people with these conditions is significantly lower than the general population. Why do you think this is the case?**

What do you consider to be the main barrier/s to employment for people living with a serious mental health condition?

What are your views on the employment of people diagnosed with a serious mental health condition working in regular mainstream jobs?

While working as an employment service provider did you assist any jobseekers diagnosed with bipolar or schizophrenia? What obstacles did you face in helping them to find or maintain employment?

While working as an art therapist did you work with anyone who had been diagnosed with bipolar disorder or schizophrenia? As an art therapist, did you gain any insights into the work-related goals or experiences of clients with schizophrenia or bipolar disorder?

In your experience how much focus is placed in treatment settings on achieving employment outcomes for people recovering from these conditions?

What has been your experience of the attitude and expectations of treating health professionals in relation to achieving employment outcomes for these clients?

Do you think social security payments influence work-related decisions among people living with a serious mental health condition? In what way?

Did you receive any form of education about mental illness at school? What form did it take?

How old were you when you first learned about schizophrenia and/or bipolar disorder?

How did this learning occur? What were the feelings associated with this learning?

#### Question 2

**What do you think would need to change in order to improve employment outcomes for people who have been diagnosed with schizophrenia or bipolar disorder?**

What would need to change for more people with a serious mental illness to find and keep work?

Do you think people with serious mental health condition get enough support to *enter* regular mainstream employment?

Do you think people with serious mental health condition get enough support to maintain regular mainstream employment?

Do you think people with serious mental health condition get *equal opportunities* in employment?

What do you think about disability versus mainstream employment services for people with mental health conditions employment services?

What improvements are needed in employment service provision for these clients?

Do you think employment services should employ peer support workers? Mental health professionals?

What impacts would there be on the community if more people with a serious mental illness were employed in mainstream jobs?

How would you feel if more employers employed people with a serious mental illness?

Do you think the employment of more people with a serious mental illness in regular jobs would affect community wellbeing? In what way? Would there be any risks?

Have you ever worked alongside a co-worker who has been diagnosed with schizophrenia or bipolar disorder?

What would be your main concerns about working alongside a person with a serious mental illness?

What support would you expect from your employer if he/she employed someone with a mental health condition?

What other adjustments might be needed in the workplace to accommodate this?

Have you ever worked in a position where you have to manage other staff? Did you receive any education or training on how to manage a staff member who has bipolar disorder or schizophrenia?

What measures are needed to overcome stigma?

Do you think that the employment of more people with serious mental illness in regular jobs would affect the stigma associated with serious mental illness in any way (i.e. increase, decrease or not affect the stigma towards these conditions)?

Do you think the formal education system could play a role in reducing societal stigma towards mental health conditions such as schizophrenia and bipolar disorder?

Do you think children should learn about mental health conditions at school?

How could this be done? At what age should this occur? Key messages? Who should decide what the key messages should be? Likely obstacles?

What reaction do you think you would get from parents? From teachers?

Any good news stories?

Anything else we have missed?

## Appendix I

## Costs and Benefits of Employment and Unemployment for People Living With Psychosis.

**Benefits of Employment**

Structure  
Mental health benefits  
Personal satisfaction  
Financial  
Meaning  
Purpose  
Social Interaction  
Self-concept  
Recognition and Status  
Normalcy  
Community benefits

**Benefits of Unemployment**

Freedom from restrictions imposed by work  
No work-related challenges or pressure  
Easier money

**Costs of Employment**

Physical demands  
Loss of freedom  
Financial costs  
Work-related Stress

**Costs of Unemployment**

Poor mental health  
De-skilling and de-conditioning  
Resumé gaps  
Social isolation  
Social Status  
Lack of purpose and structure  
Self-concept  
Financial issues  
Career progression

## Appendix J

*Work-Related Impacts of Physical and Mental Health Conditions*

Physical Conditions	Mental health Conditions
Absence from work associated with chronic illness usually elicits a sympathetic response	Absence from work due to mental health issue is commonly interpreted as unreliability
Physical disability is usually obvious and does not require disclosure	Mental illness is not easily visible and requires decisions around disclosure
Access to employment usually involves physical adaptations to the workplace e.g. wheelchair ramp and are expected of employers	Access to employment is often actively impeded e.g. employment screening procedures
Workplace accommodation needs are usually obvious and visible	Workplace adjustments are less obvious and require awareness for employers to understand
May require adjustment to the physical environment	Usually requires adjustments to management style and emotional climate



## Appendix K

## Factors Perceived to Affect Accuracy of Work-Related Assessments

**Job capacity assessments undertaken by [social security agency]**

- Stigma, fear and anxiety associated with [social security agency] and doing phone interviews means that assessment is not a relaxed process.
- Duration and depth of assessment is inadequate to elicit necessary information.
- People may not feel comfortable disclosing issues such as substance misuse in the [social security agency] environment and “real” issues may only emerge after the assessment has been completed.
- Variable levels of liaison and consultation between the assessor and other stakeholders.
- Employment consultants reported issues in relation to providing input into assessment such as having to go back to [social security] and the energy it takes to “change mind-sets”.
- Assessment process does not take into consideration the amount of work needed on part of employment consultants to get and keep clients work ready.
- Assessor may lack training in mental health or have insufficient experience or knowledge of the barriers.
- Assessment is guided by diagnosis rather than individual’s functional ability.
- Assessments are subjective as assessors are not immune to attitudes based on misperceptions. Assessors may have stereotypical beliefs around outcomes and recovery from mental illness, depending on what the diagnosis is.
- Work capacity may not be able to be determined until someone’s actually doing the job, and may depend on situational factors such as the level of support from management and colleagues.
- Lack of faith in government to provide competent assessors and cost of private assessments.
- The system is geared towards proving you can’t work.
- People stay in system a very long time before they get appropriately assessed and diagnosed.
- Under-assessment of work capacity enables people to “opt out” of employment; graduated return to work seen as a “huge hurdle” to full-time work.
- Under-assessment of funding level required to support person into work.

- Assessment of work capacity does not adequately take into account what they need to do and lifestyle they need to stay healthy-exercise, sleep, attend appointments.
- Assessment does not take into account the important role of contextual factors in determining a person's work capacity, and that the nature and extent of support afforded by managers and co-workers in the workplace can significantly increase or reduce a person's work capacity
- Over-assessment of work capacity may result in people feeling pressurised to work when they are not ready, loss of pension and forced job-seeking all of which were seen to result in stress and potential for de-compensation.
- Inappropriate referral of people who are not ready for employment; referral to mainstream rather than disability employment service provider.
- Assessment of entitlement to study payment only looks at contact hours, not how many hours are actually spent studying.

**Mental Health assessments:**

- Reviews by mental health service prior to referral for job capacity assessment were seen as "weighing it down a little bit."
- Under-assessment of work capacity by general practitioners
- Mental health professionals may dissuade people from working full time
- Lack of agreement among mental health professionals regarding criteria for determining work-readiness.

**Employment service assessments:**

- Employment consultants do not consider your qualifications when arranging job opportunities.

## Appendix L

## Cost-Benefit Analysis of Disclosure in Psychosis

**Benefits of Disclosure**

Would help the employer to understand unexplained absences from work

Access to provision of employment support-ESP, employer

Employer empathy and understanding; leniency if time is needed off work

Co-workers may be more understanding

Personal preference to be upfront

Promotes sustainable work-through enabling employer education as well as contact and communication between employer and case managers if needed

Would promote attitudinal change

Relief at not having to fabricate reasons for attendance at appointments.

**Benefits of Non-Disclosure**

Improved chances of gaining interviews and securing employment

Greater need to extend yourself which may help to build resilience. *"...if you don't disclose then you tend to push through that a bit more and stretch yourself."*

**Costs of Disclosure**

Stigma-people look at you and think you are a little bit different; categorisation, labelling, stereotyping (preconceived ideas), being judged, changed perceptions ( de-valued, less respect )

Discrimination- restricts employment opportunities (ability to secure interview, gain jobs); risks of being viewed and treated differently in the workplace including coming under closer surveillance and being subject to bullying (name-

**Costs of Non-Disclosure**

Requires additional effort to fill unexplained gaps in resumé

Increased pressure due to need to maintain constant state of vigilance to guard secrecy and hide the condition from others; need to prove you are as good as everybody else; difficulty explaining treatment needs; difficulty explaining inability to function; fear of inability to sustain work or relapse

calling, baiting, loss of employment); loss of business *"And then I find after I've got the job they watch me like a hawk. And I've found a few jobs they actually bait me to see how I'll go..."*

Negative reaction from employer-behaviour attracts closer scrutiny from employer; employer may look for problems; misinterpretation of behaviour and moods, perception that they need extra support and are harder to accommodate

People have less regard for you or hold you at a distance

Can affect social relationships in the workplace-can affect acceptance by co-workers (concerns about contagion), difficulty making friends. Avoidance. Rejection (due to fear). People "hold you at a distance". Separation.

Self-victimisation-*"...if you do disclose I think it's too easy just to become like a victim...I've got this condition, I'm not feeling too good, I'll have a day off."*

Compromise professional registration

Inability to control extent of disclosure within the workplace including how many people "need to know".

Not knowing what to divulge and what not to and how this information may be used against you later

requiring time off work

Unexplained "drugged out" appearance

Employer unaware of need for empathy and support - may affect sustainability of employment

Employer less sympathetic in event of needing time off work or support to return to work following relapse-affects sustainability of work.

Precludes informal collegial support.

Inability to access relevant employment support, particularly during periods of exacerbation or relapse

Employer unprepared to deal with situation appropriately

Employer may mistakenly think they are lazy, unreliable or refuse to give a reference

Perpetuation of stereotypes and lack of opportunity to challenge prevailing attitudes

Unsuitable or unsustainable work - setting themselves up to fail, exploitation

Dismissal for false declaration

## Appendix M

## Comparison of Specialist and Mainstream Employment Service Providers

	Specialist	Mainstream
Advantages	<p>Helps to integrate people into society by providing specialist support</p> <p>Provides post-placement support and educates employers and the community</p> <p>People need individualised attention, more time and extra care</p> <p>Need for more specialised support such as counselling</p> <p>Have different and more specific needs</p> <p>Easier</p> <p>Employer is more informed</p>	<p>Less stigma</p> <p>Focus is on the person with less prominence given to “illness” or “disability”</p> <p>Normalisation</p>
Disadvantages	<p>Potential for stigmatisation</p> <p>Segregation and categorisation of people as “disabled”; makes disability the forefront of the person</p> <p>Unless they have a specialist area in mental health may lack understanding of mental illness</p> <p>Potential to be rejected by mainstream provider and sent to DES provider-may then decide not to seek further assistance</p>	<p>People with mental illness may be disadvantaged if they have to compete with people with fewer physical, mental or social problems.</p> <p>Assistance with slip away</p> <p>Lack of scope and education to deal with people with mental illness</p> <p>Tend to be a number</p> <p>Don’t take your disability into account; requirements too strenuous</p> <p>Could be “swallowed up” in the system</p>

## Appendix N

### Recommendations

- Increase research funding to find more effective medical and psychological treatments for psychotic disorders; promote research with a positive focus on mental health recovery.
- Introduce mental health into the school curriculum from a young age to break down taboos, reduce stigma and normalise the subject of mental health.
- Encourage balanced and responsible reporting in the media including increase in positive messages and recovery stories.
- Challenge the stereotype that people living with a psychotic condition are violent, by increasing understanding of the role of co-morbid conditions (such as PTSD and substance abuse) and socio-economic factors in violent behaviour.
- Educate health professionals and human services staff on the health benefits of work.
- Educate health and allied health professionals at university level in recovery-orientated principles and practice. This would include a critical understanding of the history of psychiatry, the clinician's illusion, mental health impacts of employment and unemployment and evidence-based employment principles.
- Introduce mandatory education on mental health, including employment-related matters, in the tertiary education of lawyers.
- Introduce a mandatory component on mental health in tertiary level business/human resource management courses as well as workplace training programs for employers

and managers. This would include educating employers on their rights and responsibilities in relation to prevention of discrimination in the workplace.

- Provide training on workplace support needs of people living with psychotic conditions as part of management courses. Include information on the nature of reasonable workplace adjustments for people living with psychosis in the standard training of all management and human resource personnel.
- Improve knowledge among general practitioners and other front-line mental health workers of employment support services available to assist people to obtain and retain employment, including job in jeopardy assistance.
- Make information on community mental health services and employment support services more readily available in doctors' waiting rooms.
- Develop training resources to support people experiencing persisting psychotic conditions to gain and maintain employment, including client-developed resources.
- Shift the paradigm within the mental health service system from a focus on treating problems to a focus on helping people *flourish* in the community.
- Employ more mental health personnel in community settings in consultation-liaison roles, to proactively support people living with psychosis to maintain their well-being and lead meaningful lives in the community, including the achievement of social and occupational outcomes.
- The scope of public mental health treatment services should extend beyond symptom control and risk management to the provision of interventions that empower people to develop their self-management skills and functional capacity, and maximise their

potential to engage in study, employment and other forms of community activity including volunteer roles.

- Include motivational interviewing in routine mental health case management practice to assist clients overcome ambivalence and explore options to engage in study, work and/or social participation.
- Introduce occupational outcomes as a benchmark against which the performance of community mental health services is measured and for which they are held accountable.
- Consider the possibility of increasing channels for information sharing between federal and state departments by introducing online access to recovery plans and employment service outcome reports. This would include online access to: 1) background information considered relevant to employment; 2) occupational information contained in the recovery plan prepared by mental health case managers; and 3) employment service referral and exit reports.
- Provide access for people living with psychosis to motivational interviewing through Access to Allied Psychological Services (ATAPS) in order to address the high incidence of co-morbid substance dependency and/or to explore future options for work/study.
- Educate carers on the health benefits of work for people living with psychosis and provide “care for carers” in order to strengthen family support to achieve *sustainable* employment outcomes.



- Extend eligibility for Access to Allied Psychological Services (ATAPS) to carers to support them in maintaining their own well-being and enable them to provide quality support in their role as carers.
- Improve incentives for people on DSP to return to work. Introduce an income exemption period and raise the allowable income threshold before DSP is cancelled to give person time to build confidence in their ability to sustain employment.
- Fund employment services to employ people who have lived experience, education and/or training in mental health to assist people with psychotic conditions to obtain and maintain work. This would ensure that the client and the employer receive effective support and would reduce the demand on mental health case management services.
- Provide place-based servicing arrangements, at places familiar to clients and with the support of staff who are familiar to them, to link clients with employment services.
- Encourage DSP recipients living with a psychotic condition to explore study/work/social goals and participate in employment programs.
- Offer structured pre-vocational programs that specifically prepare people with psychosis for work and equip them with work-related self-management skills, as part of services provided by government employment providers, mental health services, non-government organisations and private psychologists.
- Allocate funding for training to improve the mental health awareness and skills of employment consultants and customer service advisors working in human services agencies.

- Employ more staff with a lived experience of psychosis.in government departments including human services such as social security and the employment service sector.
- Action referrals for motivational interviewing in circumstances where substance misuse or ambivalence impede the achievement of jobseekers' personal goals.
- Increase accountability of government-funded employment service providers for implementing evidence-based best practice in the provision of employment support services for people living with psychosis. Develop performance standards in respect of service quality and outcomes and measure performance against international benchmarks.
- Enhance employment support to access and maintain work. The focus of many employment providers is on obtaining work, however skilled support is also required to support clients to *maintain* work through episodic relapses.
- Improve opportunities for people living with psychosis to be employed *at or above award wages*. This would include review of the situation of people with persisting mental health conditions currently employed at below award wages; development, in consultation with employer organisations, of financial incentives for employers; and evaluation of the potential to expand social firms in Australia.
- Encourage large corporations to increase employment opportunities for people living with psychosis.
- Encourage business organisations to organise workshops to increase employer awareness and understanding of psychosis.
- Provide an employment support hot line for employers.

- Require government and large business corporations to have a disability employment policy in regard to employment of people living with psychotic disorders.
- Promote and subsidise mental health awareness/mental health first aid training for employers/all staff/first aid officers.
- Provide incentives for smaller firms to offer employee support programs.
- Encourage and expect employers to comply with legal requirements to make reasonable accommodations for people with long-term psychiatric conditions including provision of flexible working arrangements.